

**Getting a Needed but Unwanted Answer: The Meaning and  
Impact of a Dementia Diagnosis for Spousal Caregivers**

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## **DECLARATION**

I declare that I am the sole author of this thesis and that the work contained herein is my own. This thesis, or any part of it, has not been submitted for any other degree or professional qualification.

Aileen McCafferty

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## **ABSTRACT**

Current recommendations by the Scottish Intercollegiate Guidelines Network (Guideline 86) emphasise the need for diagnostic and post-diagnostic information and support provided to people with dementia and their family members to be tailored to meet their needs. Whilst there is a wealth of literature quantifying attitudes towards diagnosis disclosure and satisfaction with practice, there is a lack of research which looks at the impact and meaning of a dementia diagnosis for familial caregivers, despite recognition that psychological reactions to a diagnostic disclosure are critical to understand to provide appropriate information and caregiver support (Carpenter & Dave, 2004). Using a qualitative methodology, the aim of the present study was to explore the meaning of a dementia diagnosis in a spousal partner and living with the early, post-diagnostic stage.

### **Method**

Individual semi-structured interviews were carried out with 8 spouses of older adults, recently diagnosed with a dementia condition. All interviews were transcribed verbatim and analysed using Interpretative Phenomenological Analysis (Smith, 1996).

### **Findings**

Five super-ordinate themes emerged from the interviews: Getting an Answer (“You just need to get a name put to it”); Losses and Changes for Self; Changes in the Marital Relationship (Threats to Coupledom); Limiting the Emotional Impact of Diagnosis, and Preserving Normality.

### **Conclusions**

Participant accounts suggest a dementia diagnosis is something viewed as needed but is associated with unwanted implications; posing a threat to the self and the marital relationship. Post diagnosis, spouses engage in a process of making sense of and protecting themselves against the impact of changes and sensed losses. It is recommended that post-diagnostic services should aim to support spousal caregivers

as they manage these experienced and anticipated losses. Appropriate support at this time may lessen the risk of psychological distress and carer difficulties at later stages. Suggestions for future research include the need for longitudinal research starting at the time of diagnosis to explore whether the meaning and impact of a dementia diagnosis for spousal caregivers shift over time.

## 1. BACKGROUND

*“Dementia is a key health issue facing Scotland over the coming decades as our population ages. It is vital that it is recognised as such”*

The Dementia Epidemic: Alzheimer Scotland, 2007a

*“The importance of support for the carers of people with dementia through the course of the illness must not be underestimated”*

Scottish Executive & Alzheimer Scotland (2004)  
Health Department Letter 44.

*“Care of people with dementia is typically more complex and demanding than helping people with physical disabilities but no cognitive impairment”*

Zarit, Gaugler and Tarrott, 1999

At present, the estimated prevalence rates for people with dementia in Scotland are approximately 58,000 to 65,000 (Alzheimer Scotland, 2007a). With more people living longer (Kinsella & Velkoff, 2001) and the prevalence of both early- and late-onset dementia doubling with every five year increase across the age range the prevalence rate is projected to increase considerably over the coming decades (Alzheimer Scotland, 2007b). Indeed, Alzheimer Scotland’s Dementia Epidemic report estimates an approximate 75 per cent increase in the next 24 years to a projected prevalence of 102,000 to 114,000 in Scotland by 2031 (Alzheimer Scotland, 2007a). Such figures emphasise the need to prepare now to support the coming generation of people with dementia and their carers.

Recent Scottish policy documents have recommended that services provide appropriately tailored information and support for people with dementia and their carers to meet their specific needs at each stage of the dementia condition.

In the introduction to the current study, understanding of dementia and caregiving will be discussed. Reference will also be made to the relevant policy documents that provide the socio-political context for dementia care in Scotland. This chapter will then proceed to outline the literature exploring the impact of caregiving on carer well-being, discussing models of caregiver stress and coping. The final area discussed in this chapter is the dementia diagnosis literature emphasising the lack of research exploring the meaning of a dementia diagnosis in spousal caregivers and how they adjust in the early stages of the condition. This chapter will conclude with the rationale for the present study and the qualitative methodology adopted.

The background information referred to in this Introduction Chapter is the result of a literature search focusing on dementia caregivers (with particular reference to spousal caregivers). In reviewing the diagnosis and early stage of the condition variations on the following terms were used: “Dementia”, “Alzheimer’s Disease”, “Diagnosis”, “Disclosure”, “Caregivers”, “Carers”, “Post Diagnosis”, “Early Stage Dementia”, “Assessment”. The main electronic databases used included; psychINFO, EMBASE, OVID and MEDLINE, along with examination of backdated issues of relevant journals including *Aging and Mental Health*, *International Journal of Geriatric Psychiatry*, and *Dementia*.

## **1.1 Understanding of Dementia**

It is beyond the scope of this thesis to fully explore, in detail, how various disciplines (medical, psychological and sociological) have attempted to conceptualise the dementing process. Thus this section will be limited to providing a brief outline of the two main perspectives that have come to influence current dementia care.

### **1.1.1 Medical Perspective of Dementia**

The medical or bio-psychological understanding of the term dementia refers to an organic brain syndrome. This can be caused by several different disease pathologies that have as a common feature, progressive deterioration of brain tissue or nerve cell

death and associated changes in cognitive and behavioural functioning and emotional control (Lezak et al, 2004). There are two main systems of classification for the diagnosis of dementia used in the United Kingdom; the International Classification of Diseases, 10<sup>th</sup> edition (ICD-10) (World Health Organisation, 1992) and the Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> edition (DSM IV, American Psychiatric Association, 2000).

The ICD-10 defines dementia as<sup>1</sup>:

*“A syndrome due to disease of the brain, usually of a chronic or progressive nature in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded by deterioration in emotional control, social behaviour or motivation”.*

According to ICD-10 criteria, in order for a dementia diagnosis to be made there must be evidence of a decline in memory and thinking sufficient to impair activities of daily living.

The second commonly used classification system, the DSM-IV (APA, 2000) differs slightly in that it does not specify chronicity or require evidence of progression and identifies separate criteria for different dementia conditions (See Appendix I). However, both the ICD-10 and DSM-IV criteria specify that the observed impairments must not be explained by the presence of delirium or other physical or psychiatric conditions, thus these classification systems would suggest a dementia diagnosis is a diagnosis by exclusion, namely it is the remaining explanation when all other sources of confused behaviour have been ruled out (Cheston and Bender, 1999).

Although the diagnostic criteria outlined suggest common features across dementia conditions, the medical understanding of dementia holds that location of the nerve

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<sup>1</sup> International Classification of Diseases- 10<sup>th</sup> edition, World Health Organisation, (1992), page 28.

cell death, and the process and rate by which it occurs, gives the different dementia conditions their characteristic cognitive and behavioural symptoms (Halligan et al., 2003; Green, 2000; Jacques & Jackson, 2000).

The most common type of dementia, Dementia of the Alzheimer's Type (DAT), accounts for approximately 62 per cent of diagnosed cases in the UK (Alzheimer Scotland, 2007a), and is characterised by a gradual onset and continuing progressive decline in memory, language and executive functioning (Morris, 1996).

The second most common dementia sub-type is vascular or multi-infarct dementia (MID) accounting for approximately 17% of all UK dementia cases (Alzheimer Scotland, 2007a). MID is typically associated with an acute onset, fluctuating severity and a step-wise decline, affecting areas of higher cognition and motor functioning, with the severity and pattern of damage dependent on which specific cortical and sub-cortical regions are involved (Walsh & Darby, 1999).

The third common type of dementia condition is Dementia with Lewy Bodies, associated with an often mild presentation at onset, followed by highly fluctuating cognitive performance and level of consciousness, visual hallucinations, spontaneous motor features of parkinsonism and depressive symptoms (McKeith, 2002).

Rarer forms of dementia conditions include frontal-temporal dementia, FTD (approximately 2 % of diagnosed UK cases, Alzheimer Scotland, 2007a), dementia associated with Huntington's Disease, dementia in Parkinson's Disease, and infective type dementia conditions (AIDS dementia complex, Creutzfeldt-Jacob disease and neurosyphilis) which together account for approximately 5% of UK dementia cases (Alzheimer Scotland, 2007a).

Although different dementia conditions have been described with reference to discrete neuropathologies and specific neuropsychological profiles, over 10% of all individuals diagnosed with dementia in the UK are given a diagnosis of dementia of

mixed aetiology (Alzheimer Scotland, 2007a), highlighting the complexities involved in understanding the organic basis of dementia.

The diagnosis of dementia can only be certain at post-mortem, following histological examination of neural matter (Ballard, 2000). However, a possible or probable diagnosis can be made following a lengthy period of assessment and medical examination (Green, 2000). One of the main components of the assessment and diagnosis of dementia is taking a detailed history of symptom pattern, usually via interviews with the patient and family members or carers (Green, 2000). Medical examination often involves a thorough diagnostic work-up with extensive haematological tests and neuro-imaging to identify evidence of neuropathology (Dougall, Nobili et al., 2004; Dougall, Bruggink et al., 2004). Differential diagnosis also typically involves cognitive screening or more extensive neuropsychological assessment of a wide range of higher cognitive functions including memory, language, executive functioning, visual-spatial and constructional abilities (Lezak et al, 2004) with the aim of identifying a specific cognitive profile to aid in differential diagnosis (Maciejewski, 2001). Neuropsychological assessment is of particular value in cases where dementia is not clinically obvious or the diagnosis is not clear and to measure cognitive decline over time (Green, 2000).

Traditionally within the medical paradigm treatment of dementia was limited to managing the associated symptoms, namely psychiatric and behavioural disturbances, with the use of antipsychotic medication, anti-depressants or anxiolytic medication (Lancot, et al., 1998; Bains, et al., 2002). However in recent years, pharmacological advances have been made, with the introduction of Acetylcholinesterase inhibiting drugs that aim to prolong symptomatic effects and possible retardation of symptom progression (Green, 2000).

### **1.1.1.1 Critique of the Medical Understanding of Dementia**

In the past two decades there has been increasing criticism of a solely organic understanding of dementia, focusing almost exclusively on brain functioning and cognitive loss (Cheston & Bender, 1999).

One of the most significant critics of the medical model, specifically as it applies to dementia, is Tom Kitwood (Kitwood, 1990, 1993, 1997). Kitwood (1997) contends by focusing on solely organic factors (level of neuropathology and cognitive impairment) the medical model presents a limited and simplified, cause and effect understanding of the condition. Kitwood & Bredin (1992) argue a rigid organic conceptualisation of dementia fails to explain three areas of evidence relating to the dementia process: Firstly, cases of significant reversal of deterioration in functioning or “rementia”, most commonly observed when an individual’s condition of life, particularly their social relationships are positively changed. Secondly, in cases where individuals who have been clearly diagnosed with one of the main dementia conditions demonstrates relative stabilisation of function for up to 8 years from the first recognition of impairment. Thirdly, in cases where there appears to be only a loose correlation between the extent of neuropathology (observed post mortem) and severity of cognitive and behavioural symptoms.

### **1.1.2 Socio-psychological Understanding of Dementia**

One of the key proponents of the socio-psychological understanding of dementia is Kitwood (Kitwood, 1990, 1993, 1997) who, as discussed above, challenges the medical model’s “*overwhelming tendency to make the brain, rather than the personhood of the dementia sufferer its central focus of attention*” (Kitwood & Bredin, 1992; page 270). The central tenet of Kitwood’s conceptualisation of the dementia process is that the clinical presentation of dementia cannot simply be explained as a direct consequence of neurodegenerative processes or loss of neurological functioning. Rather the disorder reflects a set of interpersonal processes occurring between people when a person is diagnosed with dementia (Kitwood,



1997). These processes are hypothesised to result in the erosion of the “personhood” of the individual with dementia, as the “person” becomes “invisible”, there is a simultaneous increase in focus on the cognitive and behavioural effects of dementia (Kitwood & Bredin, 1992). Kitwood (1993, 1997) argues that the process of dementia represents a degradation or “stripping away” of an individual’s personhood. Kitwood (1997) proposes that individuals in adult life attempt to maintain a sense of well-being or self without the involvement of others, instead opting to obtain a sense of fulfilment and self-purpose by participating in projects and challenging activities. The onset of dementia means the individual may not have the capacity to plan and execute projects and therefore relies on others to continually evoke and reassure their selfhood via interpersonal interactions (Kitwood & Bredin, 1992). During the development of dementia, the “self” or “person” is “shattered” and in order to limit the devastating effects of this process, positive and supportive interactions with “others” (family, friends and staff) are needed to hold the “person” together. However, Kitwood & Bredin argue such interactions are often lacking in the lives of people with dementia, where there is typically a clear division between the non-diagnosed “we” and the diagnosed “they” who are considered damaged, derailed and deficient. This pathologisation of “they” results in the deprivation of an equal status of personhood or “depersonalisation”. This process is termed by Kitwood (1997) as a process of Malignant Social Psychology (MSP), whereby following diagnosis, people’s social world combines with their neurological impairment to erode their sense of being.

Kitwood (1993, 1997) argues that a fuller understanding of the social psychology of the dementia process helps shape the rationale for good care practice. Kitwood and Bredin (1992) advocate dementia interventions placing the preservation of personhood as a key care component, by developing empathetic and positive interactions between people with dementia and their formal and informal carers.

### 1.1.2.1 Critique of Sociological Understanding of Dementia

One main area of objection to Kitwood's conceptualisation of dementia relates to significant methodological problems with his research. Adams (1996) argues that whilst Kitwood has elaborated extensively on his views on the dementia process,

*“He spends considerably less space describing how he developed these ideas and presenting his data”*, (Adams, 1996, page 951).

Adams (1996) cites the lack of published psychobiographies<sup>2</sup> and lack of convincing empirical evidence for Kitwood's claims.

A second major criticism of this approach surrounds the overwhelmingly positive and optimistic nature of Kitwood's perspective given the inevitable negative outcome of dementia conditions and the “devastation” it may cause for the individual and their relationships with others (Adams, 1996; Davis, 2004). Additionally, whilst Kitwood's views may provide a valuable contribution in understanding moderating and mediating variables in the dementia process, they less satisfactorily explain the development of the condition (Adams, 1996). The main contribution of the sociological perspective has been to emphasise the importance in considering the social world and the impact of others on the dementia process and suggesting scope for a more positive approach to dementia care.

In summary, there appears to have been a shift in the past two decades of how dementia has come to be understood. There has been a call to move from “organic” models where the “problem” is located within the individual to placing dementia within a social context. Sociological approaches have highlighted the need to consider interpersonal factors integral to the dementia process and to explore the personal impact or meaning of dementia for the key individuals involved; namely the person with dementia and their significant others.

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<sup>2</sup> Kitwood's method of gathering information to develop this understanding of dementia involved interviewing family members about the life events of the person with dementia to construct psychobiographies or accounts of their lives.

## 1.2 Understanding Caregiving

A recent report by Dementia UK (Alzheimer Scotland, 2007b) estimates that 63.5% of people with dementia live in the community and, for many of these individuals, formal professional and informal support is essential to aid in independent community living. For many older people with chronic health conditions, including neurodegenerative disorders, help is provided first, and for the longest period of time, by family members (Zarit & Edwards, 2008). Indeed, the Signpost to Support document produced by the Scottish Executive and Alzheimer Scotland (2003) estimates approximately 29,000 people in Scotland provide regular and substantial amounts of care to family members with dementia. It is likely (given the prevalence estimates cited above) that by 2007 the number of informal caregivers will have increased further.

Defining who is a “caregiver” is a complex task. Pearlin, et al. (1990) argue that caregiving and caring acts are intrinsic to any close relationship and can refer to actions which may be found in a variety of relationships or roles such as parent-child or husband-wife. However, the emergence of a serious and chronic illness such as cancer or following increasing impairment in neurodegenerative disorders may mean the ordinary exchange of assistance and support in the relationship shifts to a more unequal exchange (Pearlin et al., 1990). Thus in such circumstances, caregiving may become the dominant component of the relationship (Pearlin et al., 1990). The situation is further complicated as individuals may define themselves as a caregiver based on very different criteria, with some who provide ongoing, daily help and practical support not identifying with the label, whilst others who provide little or infrequent help view themselves firmly within the role of “carer” (O’Connor, 2007). Despite such difficulties, research exploring the demographics of familial carers have accepted as a broad definition of a carer as someone (family member or friend) who assists or supports another individual with tasks of independent living including financial tasks, transport, health care matters, and activities of daily living including household chores and cooking as well as personal care tasks on a regular (daily or almost daily) basis (Zarit & Edwards, 2008; Moriarity & Webb, 2000). In some cases

of people with dementia, caregiving may also involve providing supervisory care, for example for those individuals, who as a result of severe cognitive impairment or disinhibited behaviour, may expose themselves to high risk situations. Using such criteria, a relatively recent demographic study of dementia caregivers, found carers were more likely to be co-residents, spouses or adult daughters, female (2:1, female: male ratio) with a mean age of 63 (Moriarty and Webb, 2000).

According to the Signposts to Support document by the Scottish Executive and Alzheimer Scotland (Alzheimer Scotland, 2003) caring for an individual with dementia presents carers with a “*unique combination of demands*” (page 13), due to the complex, unpredictable and progressive nature of the condition. As well as providing increasing levels of supervision and practical support with daily living and self-care tasks, both the person with dementia and their family members and carers may have to adjust to and cope with emotional, behavioural and personality changes. As the dementia condition progresses, family members and carers may also need to gradually take over decision making regarding financial, legally and health and social care issues.

In an attempt to profile the nature of caregiving, Aneshensel et al. (1995) refer to caregiving as a “career” and draw parallels with occupational careers. They highlight the temporal focus of both, with both “careers” usually of lengthy duration with ongoing change and growth, with experiences that build on each other. Aneshensel et al. (1995) argue that an occupational career is not a single job but rather a constellation of jobs that relate to each other, building in terms of accomplishments, acquired skills and complexity over time. Similarly, the caregiving career is not based on one act or repeating the same acts indefinitely, but rather consists of a range of responsibilities that develop over time. Dementia caregiving, in particular, fits this analogy due to the progressive nature of the condition, which means the caregiver is presented with new challenges at different stages of the condition.

### **1.3 Understanding the Context of Dementia Care and Carer Support: Scottish Policy Documents**

The integral role informal caregivers play in the ongoing care provision of people with dementia has been recognised in recent policy documents. Since its devolution in 1999, Scotland has had more independent responsibility for its own health and social policy and thus this section will focus on recent Scottish documents relating to dementia care, with particular reference to recommendations for carers. Although it is beyond the scope of this thesis to review the impact of these policies in any detail, it is important to outline them as they shape the socio-political and health-care context in which the assessment, diagnosis and the subsequent care of people with dementia occurs.

In 2004 the Scottish Executive and Alzheimer Scotland jointly authored a report highlighting the principles of good dementia services. The recommendations made in this report (Health Department Letter-44, Scottish Executive, 2004) are based on the findings of the earlier Needs Assessment Report (NHS Scotland, 2003) and the Planning Signposts for Dementia Care Services documents (Alzheimer Scotland, 2000). The Needs Assessment Report identified obstacles that may prevent the improvement of services for people with dementia and their carers and suggested ways of overcoming them. The HDL-44 proposes a template that may be used as a planning and audit tool for service provision. The template covers six essential groups of services: pre-diagnosis, diagnosis, post-diagnosis support, community services, continuing care and co-ordination and care management. The HDL-44 template emphasises the need for flexibility and to;

*“Respond to the complexity of the illness and the multiplicity of needs that people with dementia and their carers have”*  
(HDL-44, Scottish Executive, 2004, page 11).

The specific recommendations for each stage of dementia care reflect the changing demands on patients and carers as the disease condition progresses. As regards the specific needs of carers, the HDL-44 report states that services:

*“Should enable them (carers) to continue caring for the person with dementia in their own home for as long as possible; support the maintenance of a caring relationship between them and the person with dementia and help them to feel fulfilled and satisfied in their caring role”* (HDL-44, Scottish Executive, 2004, page 5).

Post diagnosis, the template recommends that services should respond by providing accessible local, ongoing counselling and emotional support for people with dementia and their carers. The goal of such interventions is to help maintain independence for people with dementia and their carers.

The most recent guideline to be published in Scotland is the Scottish Intercollegiate Guideline Network (SIGN) Guideline 86 (2006). The specific recommendations made by SIGN 86, regarding assessment and diagnosis and for pharmacological and non-pharmacological interventions for dementia, are based on a review of the research literature and the clinical experience of the guideline development working group. The guideline recommends that patients and carers;

*“Should be provided with information about the services and interventions available to them at all stages of the patient’s journey of care”* (SIGN Guideline 86, 2006, page 22),

This information should not only include issues considered relevant to clinicians but rather be tailored to the specific needs of patients and carers.

## **1.4 Impact of Caregiving**

The “career” of a caregiver is associated with many unique demands and multiple challenges. Acknowledgement of how these may impact on the well-being of carers has been recognised for several decades, with Fengler and Goodrich (1979) using the phrase “hidden patients” to refer to the spousal care-givers of disabled older people. Since then there has been an explosion of research attempting to quantify the psychological and physical impact of caring for a person with a chronic health condition.

It is beyond the scope of this thesis to give full consideration to the impact of caregiving in general (by examining the AIDS and cancer literature) thus focus will be on the impact of providing care to a family member or loved one with dementia. The reason for this specificity is firstly, the limitations of the thesis and secondly, due to theoretical influences. Where research has compared the impact of caregiving in a dementia population and other chronic conditions (HIV, cancer, physically frail older people) consistently greater levels of psychological and physical ill-health has been observed in dementia care-givers (Gallo & Lebowitz 1999; Ory, et al., 2000). Additionally, the dementia condition involves deterioration over time with significant physical and cognitive changes and the presence of behavioural problems which may impact on care-giver and care-giver/ care-receiver relationship, in a way which is not observed in other chronic conditions (Ory, et al., 2000).

#### **1.4.1 Outcome Research: Measuring the Impact of Dementia Caregiving**

When discussing the impact of caregiving, researchers have made reference to “burden”, “strain” and “stress”, with the terms typically encompassing physical, psychological, social and financial effects or status (Zarit, et al., 1986). In the literature these terms have been used interchangeably thus creating difficulties when trying to establish a shared understanding of the specific effects of caregiving. In recent decades research has attempted to explore more specific effects on psychological and physical health and well-being. As Cuijpers (2005) argues, knowledge about the exact prevalence and incidence of specific disorders among care-givers is essential to establish service needs and develop treatments adapted to the needs of this target group.

##### **1.4.1.1 Psychological Impact**

The research to date has consistently linked informal caregiving with an increase in psychological distress or negative impact on psychological well-being. Several systematic reviews and meta-analyses have identified dozens of studies that have

shown an increase in levels of depressive symptomatology (Schulz, et al., 1995; Martire & Hall, 2002, and Mahoney, et al., 2005). In a recent systematic review, Cuijpers (2005) examined the prevalence and incidence of depressive symptomatology meeting diagnostic criteria in caregivers. The results of this analysis revealed relatively high incidence and prevalence rates in care-givers of people with dementia, with prevalence rates higher in this population than those found in community samples of non-care-giver older people (Gallo & Lebowitz, 1999).

Similarly, heightened levels of anxiety have been observed in dementia caregivers, with 24% of one community sample meeting diagnostic criteria for anxiety disorders (Mahoney et al., 2005).

#### **1.4.1.2 Physical Impact**

As well as impacting on psychological well-being, caregiving has been linked to poor physical health with increased risk of cardiac heart disease (Sunmin, et al., 2003), hypertension (Shaw, et al., 1999) and mortality (Schulz & Beach, 1999). Two major literature reviews have been carried out examining the health consequences of caregiving. Schulz et al. (1995) reviewed over 40 studies that explored caregiver health status and found caregivers reported higher numbers of chronic illnesses, more ill-health symptoms and taking more prescription medications than non-carer populations. The studies included in Schulz et al.'s (1995) review relied mainly on self-reports of health status. However, a more recent meta-analysis of 23 studies examined health consequences of caregiving across 11 categories including physiological variables (levels of antibodies, immune functioning, vascular and metabolic measures and levels of stress hormones) and self-report health status (reported symptoms and illnesses, health service utilisation and medication use) (Vitaliano, et al., 2003). Vitaliano et al. found that caregivers exhibited a slight but significantly greater risk for health problems compared to non-carers with stronger risk occurring with stress hormones, antibodies and global reported health.



Two pathways or mechanisms have been proposed to account for how caregiving may influence physical health (Vitaliano, et al., 2002). Firstly, chronic stress may result in heightened levels of psychological distress affecting physiological responses such as dysregulation of the noradrenalin system and increased levels of stress hormones may, if chronic and repeated, lead to pathophysiology (Niaura, et al., 1992). In a study of depressed Alzheimer's caregivers, higher levels of depressive symptoms were associated with a greater noradrenalin response to a psychological stress task (Mausbach et al., 2005). Provision of ongoing care to an individual with a chronic degenerating condition such as dementia exposes carers to frequent stressors that may result in repeated physiological arousal (Mausbach et al., 2005). The second pathway involves the impact caregiving and its associated demands may have on health related behaviours such as poor diet and increased alcohol consumption; sedentary behaviours; limited opportunity to engage in exercise; and sleep problems (McKibbin, et al., 1999; Vitaliano et al., 2002; Gallant & Connell, 1997). Both pathways are likely to interact with levels of psychological distress to contribute to increased risk of illness and poorer general health (Vitaliano et al., 2002, 2003).

A number of conclusions can be drawn from this research: First, caregiving appears to be associated with an increase in both physical ill-health and psychological distress. Second, psychological and physiological variables are not separate, unrelated outcomes of caregiving, but rather interact to mediate the effects of the other (Van den Wijngaart, et al., 2007). Third, the research would emphasise the need for routine screening of physical and psychological ill-health in carers. Finally, whilst the research outlined above highlights the increased risk of psychiatric and physical morbidity in care-givers, such consequences are not inevitable as a number of carers do not present with psychological distress or physical ill-health directly attributable to their caregiving.

The process of how caregiving impacts on individuals is highly complex, however attempts have been made to understand the variables of caregiving that are associated with these negative consequences and how these interact.

### 1.4.2 Conceptualisation of the Caregiver Stress Process

To date, attempts to conceptualise variations in the relation between stressful or challenging events (such as dementia caregiving) and indicators of adaptational status such as psychological and physical health symptoms have drawn mainly from the work of Folkman and Lazarus (Lazarus & Folkman, 1984; Folkman, et al., 1986). Lazarus and Folkman's cognitive theory of psychological stress and coping conceptualises stress as the;

*“Relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and as endangering well-being”, (Folkman, et al., 1986; page 572).*

Central to this theory is that processes including cognitive appraisal and coping style are hypothesised to act as critical moderators of the stressor-person relationship and its immediate and long-term outcome.

There have been a number of models of stress and adjustment which have incorporated this theory to explain the impact of caregiving with different chronic health conditions including cancer patients (Gaugler, et al., 2008) and AIDS patients (Pearlin, et al., 1997) and with dementia care-giver populations (Aneshensel, et al., 1995). Due to the limitations of this thesis and the unique nature of dementia caregiving, this section will focus conceptualisation of the stress process with regards to dementia caregivers.

The stressor-coping model proposed by Aneshensel et al. (1995)<sup>3</sup> aims to capture the complexity of the stress process for dementia caregivers by firstly, identifying and describing the conditions and experiences that impact on carer health and well-being and, secondly, explaining the variations in the effects of these conditions and experiences on care-givers. Central to Aneshensel et al.'s conceptualisation is the hypothesis that stressors beget stressors. Aneshensel et al. contend that, in the case of

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<sup>3</sup> Aneshensel et al.'s (1995) model was based on a longitudinal study with series of semi-structured interviews and questionnaires with 555 informal dementia caregivers, carried out over a period of 3 years.

caregivers, the stressors involved in the direct provision of care to a person with dementia may eventually give rise to stressors outside the boundaries of caregiving. Consequently, this model makes a distinction between two categories of stressors they term primary and secondary.

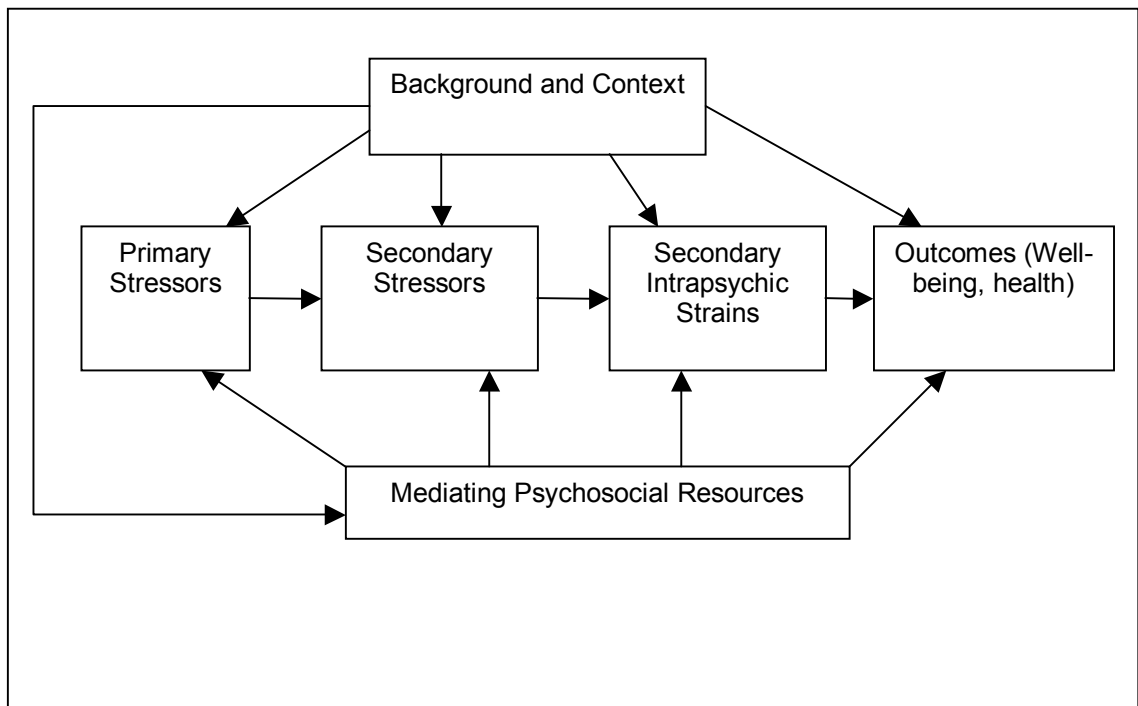


Figure 1: Aneshensel et al.'s conceptual model of caregivers' stress (Adapted from Pearlin, et al., 1990)

Primary stressors are said to be those that emanate from the condition of the person with dementia and impose demands on the caregiver to assist and support them. The concept of primary stressors includes objective and subjective stressors. Objective stressors identified by Aneshensel et al. (1995) include the level of cognitive impairment and behavioural disturbance observed in the person with dementia. The latter has been consistently linked to depressed symptoms and burden in caregivers (Gaugler, et al., 2000; Pinquart & Sorenson, 2003; Black & Almeida, 2004, and Van den Wijngaart et al., 2007). Cognitive impairment and behavioural disturbance may act as stressors by making necessary an increased level of vigilance among carers to ensure no harm comes to the person with dementia. Subjective stressors refer to the

subjective reactions caregivers have in response to caregiving acts (the personal meaning evoked by these demands). The main subjective reactions identified by Aneshensel et al. (1995) include a sense of being overloaded or held “captive” or incumbent within their role as caregiver, and a perceived loss of intimate exchange for spousal caregivers.

In this model secondary stressors are referred to as such, not as a reflection of the potency of their impact, but to highlight they are not caused directly by caregiving but arise as consequences thereof. Aneshensel et al. (1995) contend that informal caregivers often participate in other social roles and activities outside of that caregiving, including family and occupational responsibilities and engagement in leisure and voluntary activities, all of which may be placed under threat. Each of these non-caregiving activities or roles may present the caregiver with various demands, challenges and rewards. Due the increased time and energy demands associated with caregiving acts, caregivers may experience a disruption to or loss of these other roles and activities (Ory, et al. 2000; Parris - Stephens, et al., 2001). Consequently, Aneshensel et al. also identify a subjective element to secondary stressors arguing that withdrawal from valued and rewarding roles may be related to threats to caregivers’ self-identity and self-esteem.

Aneshensel et al. (1995) also identify a number of psychosocial variables, hypothesised to contribute to the magnitude of the relationship between stressor variables and psychological and physiological outcomes (either expanding or contracting care-related stressors). The main psychosocial resources incorporated within this model include social support and coping style. There has been a wealth of literature examining the role of these variables in the caregiver stress process, however the scope of the current research does not permit full analysis of these findings.

Social support refers to both instrumental support (assistance with practical tasks of caregiving) and emotional or expressive support (the availability of a trustworthy and positive confidant) (Zarit & Edwards, 2008). The influence of social support on

caregiver stress is complex with some studies finding an association between high levels of social support and positive social support and caregiver well-being (Biegel, et al., 1991; Kramer, 1997) and others reporting no such association (Stommel, et al., 1990). Aneshensel et al. (1995) also found a negative relationship with social support; with receiving help from others tending to exacerbate perceived role overload.

Two main categories of coping strategies have been explored within caregiver research: problem focused coping (finding out about the stressor and acting to change the “reality” of the situation) and emotion focused coping (changing the “meaning” attached to the situation and regulating the emotions tied to the stressful situation) (Lazarus & Folkman, 1984). Caregiving coping literature has consistently associated avoidant coping (a type of emotion focused coping) with increased depressive and burden symptoms (Fingerman, et al., 1996; Almberg, et al., 1997; Powers, et al., 2002). Practical or problem focused coping has been associated with lower levels of distress (Almberg et al., 1997). However, Zarit and Edwards (2008) argue that the efficacy of a coping strategy may depend on the nature of the stressor, and in the case of caregiving, where some aspects of the stressor are not readily modifiable, strategies which manage meaning may be more effective.

Aneshensel et al. (1995) emphasise that the role of psychosocial resources in the stress process is complex and influenced by caregiver variables; for example spousal caregivers receive more instrumental support than adult-child caregivers, whilst the opposite is true for socio-emotional support. Additionally, female carers are more likely to use emotion focused coping (Almberg et al., 1997).

### **1.4.3 Critique of Conceptualisation of Caregiving Stress Process**

The development of the above model by Aneshensel et al. (1995) has represented an advance in the attempt to understand the impact caring for a person with dementia can have on the carer. Aneshensel et al.’s work moves beyond the conceptualisation

of caregiving as a uniform stressor by incorporating social and interpersonal variables and acknowledging the dynamic nature of the care-giving process. Additionally, these models have been of value in providing a framework for caregiver interventions (Section 1.4.6).

However, there are a number of limitations to coping-stressor approach literature. The stressor-coping research predominantly uses quantitative measures of symptoms associated with specific or discrete syndromes of psychological distress such as anxiety, depression or burden. However, as Schulz et al. (2003) highlight, caregivers do not typically fall into single syndromal categories and, although most have elevated levels of depressive type symptoms, the majority of carers do not meet the criteria for clinical case-ness for depression. Similarly stressor and mediator variables are explored using discrete and specifically operationalised terms and quantitative measures, possibly omitting potentially important variables or caregiver resources that are used but have not been operationalised (Farran, 1997). A second criticism of the stressor-coping literature is the failure to consider possible differences between caring for those in the early, post diagnostic stages and those who have been carers for many years, post diagnosis. It is possible that there are unique features associated with different stages of the caregiver process and caregiver resources, appraisals and coping strategies change as the condition of the person with dementia changes. Powers, et al. (2002) carried out a longitudinal study of shifts in caregiver's coping styles over a six month period. Their findings indicate a degree of stability in coping styles, however again the focus was on mid stages of caregiving, with an average time of 4 years since diagnosis. Despite these concerns, the understanding of the impact of caregiving remains predominantly focused on caring within the latter stages of the dementia condition (Zarit & Edwards, 2008).

#### **1.4.4 Positive Aspects of Caregiving**

A third major limitation of caregiving research is the overwhelming focus on the “negative” consequences of caregiving. The models of caregiver coping which dominate understanding in the field acknowledge that positive appraisals can be

made of caregiving (Aneshensel et al., 1995; Cohen, et al., 1995; Schulz, et al., 2000). However the physical and psychological consequences associated with such appraisals reflect merely an “absence” of negative consequences (lower levels of depressive symptoms or burden) as opposed to the presence of positive reactions or consequences. Indeed, Farran (1997) contends that such “adaptation” models imply that care-givers adjust to their situation but do not consider the possibility that individuals may “go beyond” this to find positive aspects of a potentially stressful situation or transform the situation into something new such as a sense of satisfaction in caring for another or personal growth.

Kramer (1997) argues that exploring the positive aspects of caring has important clinical implications. Hilgeman, et al. (2007) propose that effective interventions should identify and target individuals with low levels of positive aspects of caregiving as these individuals may have difficulties in making positive appraisals of their situation and therefore may benefit from targeting such skills.

A number of studies suggest that a significant proportion of carers report positive reactions to caregiving including satisfaction and deriving a sense of purpose and fulfilment (Nolan & Grant, 1992; Lundh, 1999). A recent study by Marayan, et al. (2001) found one third of a sample of 50 spousal care-givers agreed “a little” or “a lot” that they had experienced “good things” from caring for their partner with dementia. The same sample also reported negative feelings towards their role as a caregiver with 67 per cent reporting feelings of being trapped in their role. Similarly, Andrén & Elmstahl (2005) found a high proportion of carers rated high levels of satisfaction with their role as a caregiver irrespective of their perceived level of burden. These studies suggest positive and negative subjective responses to caregiving can co-exist and be simultaneously experienced by caregivers.

### **1.4.5 Caregiver Interventions**

Within the past two decades there has been a significant increase in research examining the efficacy of interventions to address the negative impact of caregiving

on the carer. According to Sorenson, et al. (2002) the focus of caregiving interventions can be divided into two main categories: those aimed at reducing the amount of care provided by the caregiver (addressing the stressor) and those aimed at improving caregiver well-being and enhancing coping skills (addressing mediator / moderator variables). The former type of intervention operates on the premise of reducing the (primary) stressors the carer is exposed to such as the provision of respite care or enhancing the competencies of the person with dementia, consequently reducing their dependency on the carer. The premise of the second category of intervention is to lessen the impact of stressors by enhancing the psychosocial resources available to caregivers, namely by building on the carer's coping skills or altering the appraisals made by carers (through psychoeducation or psychotherapy).

A recent meta-analysis was carried out by Sorenson et al. (2002) to examine the differences between specific types of interventions (psychoeducation interventions; support groups; respite or adult day-care; psychotherapy; interventions to improve care-giver competency and multi-component interventions). In Sorenson et al's analysis, psychotherapy and psychoeducation interventions were associated with the most consistent and the largest average effect sizes across a range of outcome domains (burden, subjective well-being, knowledge and coping and care-receiver symptoms). Sorenson et al. reported that individual-based interventions yielded greater effects on depression, well-being and burden than non-individualised interventions, possibly because the former allows for topics and methods to be adapted to specific caregiver concerns. However, group treatments were found to have a greater positive impact on care-receiver symptoms, which Sorensen et al. hypothesise reflects the scope within a group setting to exchange caregiver strategies to cope with care-receiver behaviours or difficulties. Additionally, Sorenson et al. found that spousal caregivers generally benefited less from interventions than adult children. The authors hypothesise that adult caregivers derive greater therapeutic benefits as they are often less prepared for caregiving than spouses who may have already cared for their own parents or a sibling. Thus interventions which focus



predominantly on the provision of information and developing appropriate coping strategies may be more relevant to the “novice” adult child caregiver.

A more recent meta-analysis carried out by Gallagher-Thompson and Coon (2007) included 19 studies that met criteria for “empirically validated” treatments for reducing distress and improving well-being of carers. Gallagher-Thompson and Coon focused their analysis more specifically on psychological interventions; psychoeducation, psychotherapy-counselling (CBT, Behaviour Therapy, supportive counselling) and multi-component. The largest effect sizes were found for psychotherapy, with a CBT approach associated with the greatest reduction in depressive symptoms.

The findings of both the Sorensen et al. (2002) and Gallagher-Thompson and Coon (2007) reviews argue against “one size fits all” approach to caregiver interventions, with different outcomes achieved depending on the nature of the intervention and features specific to the care situation (including nature of the caring relationship).

Whilst the studies included in the above reviews point towards the general effectiveness of psychological interventions in reducing caregiver distress and promoting well-being, there are significant limitations to the caregiver intervention research. First, there are no studies that explore whether specific treatment approaches have differential effects on different caregiver groups (such as spousal versus child carers). Second, few studies control for the time since diagnosis or stage of dementia condition, despite Gallagher-Thompson and Steffen’s (1994) finding that brief psychodynamic psychotherapy was more effective for carers in the early stages of the dementia condition, and CBT more effective in the later stages. These areas require further exploration considering recommendations that interventions be tailored to specific caregiver needs at each stage of the dementia process (See Section 1.3).

## **1.5 Caregivers and the Diagnosis of Dementia**

### **1.5.1 Acquisition of the Caregiver Role: Disclosure of Diagnosis**

Caring for an individual diagnosed with dementia is not a single stressor or event (Aneshensel et al., 1995), but rather a dynamic, evolving process which changes over time influenced by factors that relate not only to the person with the diagnosis (fluctuations or deterioration in their condition) or the caregiver (as they augment coping responses or access new resources), but also situational changes (such as changing social circumstances and finances), (Zarit & Edwards, 2008).

Aneshensel et al. (1995) propose three transitional periods, associated with specific events, hypothesised to shape the course of caregiving. These transition periods are: role acquisition (recognising the need for the role and the assumption of its obligations and responsibilities); role enactment (the performance of role-related tasks within the home or formal care facility) and role disengagement (the cessation of caregiving usually following the death of the person with dementia and the return to other venues of life). According to Aneshensel et al. carers move along these transitions at different rates with different costs and psychological, social and material challenges.

Not all carers experience transitions in the same sequence and under identical conditions and not all transitions are experienced (for example, not all people with dementia move into residential care) (Alzheimer Scotland, 2007a). The first transition point (entry into the role of carer) is one that almost all caregivers experience, albeit in different ways. In general the transition into the role of carer is a gradual process following increasing impairment in the person with dementia and the carer's growing awareness of this (Smith & Beattie, 2001). Despite the insidious nature of role acquisition in dementia carers, this period is associated with specific

transition events which may crystallize a change in the status and responsibilities for the dementia carer, making concrete the anticipated progressive decline in their family member or loved one's functioning (Zarit & Edwards, 2008; Bamford, et al., 2004).

The assessment and diagnosis of dementia may be considered such an "official" transition event for, as Carpenter and Dave (2004) argue, receiving a "label" of dementia may make this a "*more prominent part of an individual's identity*" (page 156), for the person with dementia. This may have a number of possible consequences for family and spousal carers; firstly, they may become focused on providing practical care and support to the person with dementia, possibly at the expense of their own needs being met. Secondly, they may be recognised as having caregiver status by others including health professionals and related services and family members and friends which may have implications for their social interactions. Such implications suggest that the time of diagnosis disclosure may be viewed as an opportune time for psychosocial and educational interventions with the goal of maximising the resources of both the person with dementia and carers (Aneshensel et al., 1995; Moniz-Cook & Woods, 1997; Woods et al., 2003, and Health Department Letter-44, Scottish Executive, 2004). Moniz-Cook & Woods argue that timely and appropriately tailored patient and carer support at the time of diagnosis may help alleviate and perhaps even prevent later difficulties. Additionally, research indicates that timely information, counselling and training for carers may also enable them to continue to provide support for the person with dementia at home for longer periods (Mittleman, et al., 1993).

The significance of the diagnosis and post diagnosis period warrants further examination of this process for the central figures involved. By obtaining a better understanding of the challenges of the diagnosis and post-diagnosis stages services can more appropriately tailor information and support to meet the needs of people with dementia and their carers at this time (Health Department Letter-44, Scottish Executive, 2004).

### **1.5.2 Attitudes and Reported Practice in Dementia Disclosure**

To date there has been a wealth of information that has explored the disclosure of a dementia diagnosis, examining the views of people with dementia and, more frequently, the views of carers. The research with carer participants has, to date, predominantly focused on attitudes regarding disclosure (whether to inform the patient or not), carers' views on the benefits and disadvantages of disclosure and finally, reported practice and satisfaction with services (Bamford et al., 2004; Carpenter & Dave, 2004).

The existing research literature presents a range of opinion towards dementia diagnosis disclosure amongst carers. Studies report between 17 to 96 per cent of carers surveyed favoured disclosing the diagnosis to the person with dementia or agreeing that the disclosure was beneficial for the person with dementia or the carer themselves (Maguire, et al., 1996; Barnes, 1997; McWilliams, 1998; Smith, et al., 1998; Bachman et al., 2000; Holyroyd, et al., 2002; Pinner & Pierre-Bouman, 2002; Dautzenberg, et al., 2003; Fahy, et al., 2003; Pucci, et al., 2003; Byszewski, et al., 2007). Closer examination of this research would suggest a shift in attitudes to disclosure over time. Studies carried out in the 1990's (Maguire et al., 1996; Barnes, 1997 and McWilliams, 1998) reported between only 17 to 57 per cent of carers wanted the person with dementia to be informed of their diagnosis. However more recent research studies report that 69 to 96 per cent of carers wished for the person with dementia to have their diagnosis disclosed (Bachman et al., 2000; Holyroyd et al., 2002; Pinner & Pierre-Bouman, 2002; Dautzenberg et al., 2003; Fahy et al., 2003; Pucci et al., 2003 and Byszewski et al., 2007). This shift towards a more positive or accepting view of dementia diagnosis disclosure echoes patterns in the early cancer literature (Novack, et al., 1997; Kirby & Maguire, 1998 and Downs, 1999) when it was common for clinicians and carers to withhold a cancer diagnosis with the wish to protect the patient from distress and concern. This development in dementia care may reflect a changing awareness and understanding of the condition due to

increasing media coverage and a growing recognition of the benefits of a timely diagnosis (Pinner et al., 2002). With the recent development and availability of cholinesterase inhibitor medication, disclosure may be viewed by carers and physicians as necessary to facilitate effective management of symptoms (Connor & Epstein, 1999).

The second major focus of the diagnosis research examines the perceived advantages and disadvantages of disclosing a diagnosis to the person with dementia. The most commonly perceived positive consequences reported by carers include: to protect the patient's autonomy or "right to know", the need to avoid secrecy and misunderstanding and to maintain an open and honest relationship with the person with dementia, to help the person with dementia understand their difficulties and ease acceptance of assistance, to facilitate treatment decisions in particular access to medication and appropriate support services and to allow planning for the future (legal and financial decisions and whether to continue driving). Perceived negative consequences of diagnosis disclosure include concern that the knowledge could trigger depression, anxiety and even suicidal thoughts in the person with dementia, a belief that the person with dementia may not understand or remember the diagnosis, the belief that there was "no point" to obtaining a diagnosis as treatment options appeared limited and finally, to protect the person with dementia from the stigma attached to the condition (Connell & Gallant, 1996; Maguire et al., 1996; Husband, 1996; Barnes, 1997; Smith & Beattie, 2001 and Holyroyd et al., 2002).

Thirdly, the research has focused on what information has been provided to carer and patient and their satisfaction with this. Whilst there appears to be a more positive view of disclosure to the person with dementia and this is reflected in practice (Carpenter & Dave, 2004; Bamford et al., 2004), research indicates that even when a diagnosis is made, patients and their families do not receive the required levels of information particularly about prognosis and access to support services (Rao, 1997; Glasser & Miller, 1998 and Bruce & Patterson, 2000). When information is provided, there can be confusion about the terminology used (Bruce & Patterson, 2000) and the diagnosis may be given in a way that adds to the distress of those

involved (Chenowith & Spencer, 1986). Some studies report that due to a possible drive amongst clinicians to protect someone from distress (either the patient or carer) there is little sharing of information or limited opportunity to discuss the information in any depth (Husband, 1996; McWilliams, 1998; Heal & Husband, 1998).

### **1.5.3 The Impact and Meaning of a Dementia Diagnosis**

The main focus of the above research examining the onset and diagnosis of dementia has focused predominantly on practice reports and attitudinal study (Carpenter & Dave, 2004, and Bamford et al., 2004). However, in recent years there has been an increase in research exploring the impact of receiving a diagnosis. Namely, what are the unique challenges associated with the early, post-diagnosis stage and how do individuals make appraisals of, and cope with, these changes?

#### **1.5.3.1 Perspectives of the Person with Dementia**

Pearce, et al. (2002) interviewed 20 men in the early stages of dementia of the Alzheimer's type to gain an insight into how people cope with the onset of the condition. The interviews, analysed using an Interpretative Phenomenological Analysis, suggested that in the early, post-diagnostic stage, the men were in;

*“A process of balancing the tension between wishing to maintain an existing or prior sense of self and needing to reappraise and reconstruct a sense of self in light of changes in cognitive, environmental or social factors”* (Pearce, et al., 2002, page 186)

The accounts given by participants (supported by accounts given by their wives) suggested that specific coping strategies are associated with these two processes. The men's wish to maintain a previously held self identity was linked with adopting practical and emotion focused coping strategies such as minimising the impact of memory impairments, relying on their wives more and engaging in increased efforts to perform at a previous level of functioning. The second process of reappraisal of abilities and relationships with others was associated with developing different expectations and roles and adjusting to a sense of loss. As part of the process of reappraisal and reconstruction the person with dementia gradually becomes less

protective of their old sense of self, letting go of the old to allow room to integrate the new. Pearce et al. (2002) described this as an ongoing, cyclical process of ongoing appraisal as the person experiences new losses and engages appropriate coping strategies. This study represents a move beyond measuring levels of awareness in the person with dementia and relying solely on neurological explanations. Rather “limited” awareness may be considered to reflect an adaptive or protective psychological mechanism rather than a symptom of the condition.

A similar study carried out by Clare (2003) explored the level of awareness and meaning attached to the memory problems experienced by 12 individuals in the early, post-diagnosis stage of Alzheimer’s disease, and how they cope and adjust to these changes. Participants were interviewed on two separate occasions approximately three months apart with the function of following up whether responses had changed over time. Once again the participants’ accounts were analysed using Interpretative Phenomenological Analysis. The accounts given on both occasions indicated that adapting to changes in memory functioning involved five interrelated processes: registering changes, reacting to them, finding ways to explain these changes, experiencing the emotional impact of the changes and attempting to adjust to them. Although all participants acknowledged experiencing memory problems, they differed in the meaning assigned to or impact of their memory impairments and in the coping strategies they adopted. In general participants’ adjustment to the changes in the early, post-diagnosis stage were said to form a continuum running from “self-maintaining” (attempting to normalise the situation and minimise difficulties) to “self-adjusting” (attempting to confront their difficulties and adapt their sense of self accordingly). Clare emphasises the need to consider beyond a solely biological or neurological understanding of dementia, for to do so would be;

*“To ignore the unavoidable fact that dementia happens to a person, a self, who brings to the situation a range of resources and preferred ways to respond that in turn influence the expression of awareness in different contexts.” (Clare, 2003; page 1027)*

Together these studies suggest that the onset of dementia can place significant demands on the coping resources of the person with dementia. The disclosure of a diagnosis can have a major impact on this process as the individual gradually becomes aware of, and begins to accept the impairments and losses associated with the early stages of this condition. Additionally, a crucial task for people in the early, post-diagnosis stage involves adjusting to the meaning a dementia diagnosis has for their self-identity. The above studies suggest this to be a time of tension between maintaining a prior sense of self (or continuing with “life as before”) and recognising the changes that dementia brings and incorporating this into a new identity. These findings may be understood with reference to Kitwood’s theoretical framework which proposes that the onset of dementia poses a threat to the individual’s sense of self (*See section 1.1.2*).

The above studies also signify a shift in the nature of dementia research. There has, in the past decade, been a growing call for the need to explore the perspective of the person with dementia (Kitwood, 1997; Cheston & Bender, 1999). The two studies described above attest to the feasibility and importance of this approach. In this way, dementia research has expanded to begin recognising the importance of understanding the meaning and impact of the diagnosis for those involved.

### **1.5.3.2 Perspectives of Couples**

Building on the growing literature exploring the impact of diagnosis on the person with dementia, recent research has acknowledged the need to place this process within a relationship-based context (Zarit & Edwards, 2008; Lyons, et al., 2002, and Charlesworth, 2001) in recognition that dementia occurs within a social world. In response to this there has been an emergence of studies that have examined how families, in particular married couples, come to understand and respond to the onset of dementia.

Robinson, et al. (2005) investigated, using Interpretative Phenomenological Analysis, shared psychological reactions and experiences of receiving a dementia



diagnosis. Based on interviews with nine couples where one spouse had received a dementia diagnosis, Robinson et al. describe a cyclical process whereby couples move between making sense of the early stages, associated with denial and minimisation of problems, and acknowledging and adjusting to a sense of loss. Acknowledgement of loss included descriptions of loss of cognitive functioning, loss of independence, previous roles and associated feelings of depression and frustration. By attempting to capture the early experiences of a dementia diagnosis in the context of a marital relationship, this study has moved beyond previous studies that have incorporated spousal carers only as a means of substantiating the person with dementia's account. This study provides some insight into how the diagnostic experience impacts on caregivers themselves. However, there are important methodological limitations to this research that may have influenced the accounts given by caregivers. With qualitative methodology, the research context can have a significant impact on the nature of the account given and how this is interpreted (*See section 2.5.1*). In this study, both care-giver spouse and the spouse diagnosed with dementia were interviewed together, which as Robinson et al acknowledge may have influenced what each spouse felt willing and able to say about the situation. Spouses may have wished to position themselves in certain ways so as to prevent distressing their partner or induce feelings of guilt.

Additionally, both the accounts of the person with dementia and their caregiver spouse were analysed together to produce a single "account" which attempts to encapsulate the experiences of both within the same themes. However, Robinson et al. (2005) acknowledge that the person with dementia and their care-giver spouse differed in aspects of their accounts of the diagnostic experience, for example in perceived benefits of the diagnosis and in the particular nature of the losses encountered. Thus their study combines the experiences of both caregiver and person with dementia, despite the possibility that their experiences may differ in qualitatively significant ways.

## 1.6 Current Study

The three studies discussed in Section 1.5.3 have all used an IPA approach in exploring the impact and meaning of a dementia diagnosis on the person with dementia as an individual and as part of a couple. Qualitative approaches such as IPA are particularly relevant to answering this type of question. Whilst the focus of quantitative research is on facts, looking for causality and fundamental laws, qualitative approaches focus upon meaning and interpretation, looking instead to answer questions such as “What is X?” and, “How does X vary in different circumstances and why?” (Gibson, et al., 2004; Pope & Mays, 1995).

According to Gibson et al. (2004) qualitative approaches have a number of characteristics that make them particularly valuable to dementia and care-giving research. First, qualitative research is participatory in nature, allowing individuals to have a “voice”, and as such may be relevant for an older people population (such as dementia spousal carers) who may feel their contribution is irrelevant or ignored. Second, due to its reflexive nature, qualitative research encourages reflection that may open up new lines of thought. Third, qualitative research can be complementary to quantitative research such as enhancing the knowledge already acquired regarding disclosure practice and attitudes. Finally, qualitative approaches help aid understanding of social phenomena as they occur in natural settings;

*“Giving due emphasis to the meanings, experiences and views of all participants”* (Pope & Mays, 1995, page 44).

In the quantitative studies discussed in section 1.5.2, we do not learn about the meaning and impact a dementia diagnosis has specifically for carers, and how they cope with this. In the qualitative research conducted, the role of family caregiver has been previously to “triangulate” or support the accounts given by the person with dementia, with no account of the carers’ own individual experience.

As discussed in section 1.5.1 carers' experiences of the diagnosis and post-diagnosis stage are poorly understood, yet this may have implications for post-diagnostic support and intervention.

The current study aims to explore, using semi-structured interviews with spousal caregivers, the particular experience of gaining a dementia diagnosis for one's spouse and living with the early post diagnosis stage of the condition. This study will be a qualitative investigation as it is anticipated this will facilitate a greater depth of knowledge about the diagnosis experience for spousal caregivers, how they make sense of and the meaning they attach to this experience, and the strategies they use to adjust. It is hoped that focusing solely on the views of spousal caregivers, and by using a qualitative approach, will allow for a more in-depth understanding of the post-diagnostic stage, thus enabling services to tailor information and support more appropriately.

## **1.7 Aim**

The aim of the current study is to explore the meaning of a dementia diagnosis in a spousal partner and the experience of living with the early, post-diagnostic stage.

## **2. METHOD**

### **2.1 Design**

The current study employed a qualitative design. The method chosen for this study was Interpretative Phenomenological Analysis (IPA) (Smith, 1996; Smith & Osborn, 2003; Smith & Eatough, 2007).

With the aim of exploring the experience of a dementia diagnosis for spousal caregivers, two qualitative methods could have been adopted: IPA and Grounded Theory (founded on the principles of Glaser & Strauss, 1967). Whilst Grounded Theory has an advantage in that it is a better known and more established qualitative method (Willig, 2001), IPA was deemed more appropriate for the current research question. The primary aim of Grounded Theory is to develop an explanatory theory on the basis of the data. With IPA the aim is less on *why* people experience their world in particular ways, the main concern is rather to provide a detailed description of the quality and texture of the participant's lived experience or meaning (Willig, 2001; Smith & Eatough, 2007). As the aim in the current research was to capture an understanding of the experience and meaning of a dementia diagnosis and living with the early, post diagnosis stage of dementia in a spousal partner, IPA was selected as the most appropriate qualitative methodology for this question.

#### **2.1.1 Interpretative Phenomenological Analysis (IPA)**

According to Smith (Smith, 1996; Smith & Eatough, 2007) IPA is founded based on a phenomenological philosophy. Phenomenology focuses on how an individual experiences the world within particular contexts. According to Willig (2001) the phenomenological perspective does not make objective claims about the world, but contends that "the world" and "the person" are indivisible and the world can only be understood in terms of how a person perceives it.

As well as being grounded within phenomenological philosophy, IPA is also “interpretative”. Smith (Smith, 1996; Smith, et al., 1999; Smith & Eatough, 2007) states that whilst the aim of IPA is to gain an account of the participant’s “worldview” it is never possible to gain direct or complete access to the person’s psychological world and thus IPA involves a level of interpretation by the researcher. As it is impossible for the researcher to completely suspend his/ her own beliefs, experiences and possible biases, the process will inevitably be complicated by the researcher’s preconceptions. Thus it is essential for the researcher to engage in ongoing critical examination and reflection on his or her engagement with the text (Willig, 2001). In this way, IPA has connections to hermeneutics (Ricoeur, 1970, cited in Smith & Eatough, 2007). Smith and Eatough (2007) argue that IPA involves a double hermeneutic, whereby the participant is trying to make sense of or find meaning in his or her experiences, whilst the researcher is trying to make sense of how the participant is making sense of his or her experiences or world. Thus IPA combines empathic hermeneutics (in that the researcher attempts to take the viewpoint of the participant by close examination of the transcript), with questioning hermeneutics (allowing the researcher to hold a more detached stance to enable a more critical interpretation of what the participant says or is trying to say).

IPA has been increasingly applied within Clinical and Health Psychology, across a range of patient groups and different research questions. This method has been used with a sample of older people to explore the impact of losing a partner (Golsworthy & Coyle, 1999). More recently, this method has been used to explore coping with a diagnosis in dementia patients (Pearce, et al., 2002; Clare, 2003; Robinson et al., 2005), thus it has been established as a suitable method for this participant population and research area.

## 2.2 Participants

### 2.2.1 Participant Characteristics

Eight participants took part in the current study (seven females and one male). Ages of participants ranged from 60 to 77 years. A brief overview of participant demographics may be found in Table 1.

Table 1: Participant demographics including age, sex, years married, time since diagnosis and type of dementia condition

Participant	Age	Sex	Years Married	Time Since Diagnosis	Dementia Condition
P01	69	Female	50	11 months	Vascular
P02	60	Female	40	6 months	Alzheimer's
P03	59	Female	42	9 months	Subcortical
P04	72	Female	53	15 months	Alzheimer's
P05	73	Female	50	4 months	Mixed
P06	74	Female	48	2 months	Alzheimer's
P07	77	Male	17	5 months	Vascular
P08	72	Female	35	4 months	Alzheimer's

All participants had adult children who lived within a close geographical distance. P01 also had one adult child living at home. All participants were retired from full-time employment, however a small number worked on a voluntary basis (P02 & P05). All participants were informed of their spouse's dementia diagnosis. The spouses with dementia were also aware of their diagnosis. This information is important to consider as in previous decades, not all dementia patients were informed of their diagnosis (Carpenter & Dave, 2004; Bamford et al., 2004). Spousal caregivers whose spouse is unaware of their diagnosis may have a qualitatively different

experience to those cases where both partners are informed of the dementia diagnosis.

### **2.2.2 Method of Sampling**

Qualitative methodologies including IPA differ from quantitative means of sampling which tend to rely on random sampling in order to maximise generalisability of the findings.

With qualitative research the aim is to examine the experience of a specific or clearly defined group thus purposeful sampling may be appropriate (Smith & Eatough, 2007). In this case the aim of the research was to examine the experiences of spousal caregivers, whilst there may be some commonalities with other types of caregiver-care-recipient relationships, there may be important qualitative differences which may impact on the experience under question and thus the sample was limited to spousal caregivers who were currently living at home with their spouse with dementia.

### **2.2.3 Inclusion Criteria**

Participants were spousal carers of older adults (aged 65 and above) who have been diagnosed with dementia, over two months previously and within the past two years (See Appendix II for a full list of Inclusion and Exclusion criteria). These time limits were set so as to preserve recollection of the diagnosis whilst not asking participants to discuss an experience which is so recent as would be particularly distressing to discuss.

### **2.2.4 Sample Size**

Unlike quantitative methodologies the concept of statistical power does not apply in qualitative research. According to Smith and Eatough (2007) IPA studies are usually



conducted with relatively small samples. With IPA sample sizes are guided by striking a balance between allowing a more in-depth analysis with exploring a full range of issues with a larger sample size.

Turpin, et al. (1997) argue that six to eight participants is sufficient for clinical and health psychology post-graduate programs.

### **2.2.5 Recruitment**

Recruitment began in February 2008. The local area Early-stage Dementia Co-ordinator was asked to identify spouses of patients who have been diagnosed with dementia within the previous 24 months. The Early-stage Dementia Co-ordinator (based within the social-work department) works across three Community Mental Health Teams and visits patients who have recently been diagnosed with a dementia condition and their families.

The Early-stage Dementia Co-ordinator was provided with a copy of the participant eligibility criteria and copies of Participant Information Sheets and contact details for the researcher (Appendices II & IV). Potential participants who met the eligibility criteria were provided with a Participant Information Sheet which outlined the rationale for the research and the nature of participant involvement. An independent contact person was included on the Participant Information Sheet as a source of impartial advice to participants.

Potential participants contacted the researcher by phone to discuss the study and arrange a pre-interview meeting.

The pre-interview meeting was an opportunity for the researcher to meet with participants to discuss involvement and any concerns the participants had. Written consent was also obtained at this meeting.

## **2.2.6 Research Context**

It is recommended in qualitative research to have some information regarding the context in which the research was carried out (Yardley, 2000).

In this study the research context will be discussed in terms of the nature of the dementia services within the NHS trust where the research took place. Additionally relevant background information about the researcher will be provided.

In the NHS Trust where this research took place, most people who seek a dementia diagnosis or following concerns about possible dementia will first visit their General Practitioner (GP). Following initial examination and assessment by their GP, patients are referred to a specialist Old Age Psychiatrist for cognitive screening, and in some cases for neuropsychological assessment by a Clinical Psychologist. Once assessed by the Old Age Psychiatrist and following completion of investigations, a diagnosis will be made and given, usually by this professional. In the region where this research took place, there is an Early Stage Dementia Service (ESDS) that provides support, education and monitoring by a co-ordinator for people in the early stages of the condition (Early Stage Dementia Co-ordinator). This individual works closely with the voluntary sector, namely Alzheimer Scotland to provide additional support to patients and their families. In this region, the prescription and monitoring of Cholinesterase Inhibitor medication is available and six of the spouses with dementia were prescribed this at the time of the study.

Making explicit the context in which the research took place also involves making the reader aware of any factors which influence the objectivity of the researcher (Yardley, 2000).

In this study, the researcher has worked in the Older People Psychology service for her elective placement. In this professional capacity the researcher has been involved in the dementia assessment process and has, in a number of cases, with the Older People Psychiatrist, disclosed a diagnosis to patient and family members. Although,

the researcher was not involved in the care of any of the participants or their spouses, this study raised issues which made her reflect on her own professional role in this process.

## **2.3 Procedure**

### **2.3.1 Pilot Interview**

In deciding upon the interview questions advice was sought from a Clinical Psychologist with experience in qualitative research.

A pilot interview was carried out. Participant feedback was sought following this regarding the participant's view of the interview process. The transcript was also examined by a Clinical Psychologist experienced in research with older people. The feedback from both these sources did not indicate that revision of the interview questions was required.

### **2.3.2 Data Collection**

The interviewer met with potential participants prior to the data collection and provided them with consent forms. Once consent was obtained participants were given a two week period in which to re-consider participation. No participants withdrew at this stage.

Participants were offered the opportunity to conduct the interview in their own home or at their GP's practice. The offer to conduct the interview within the participant's home allows for greater convenience as some participants lived in rural areas and did not have access to their own transport. Additionally, Smith (1995) argues that carrying out the interview in a familiar environment such as their own home may make participants feel more comfortable and therefore be conducive to the interview. However, it was important to give participants the option to be interviewed outside

the home, as the home environment may not have offered the same freedom to discuss issues openly. Participants were reminded of the limits to confidentiality prior to commencing the interview<sup>4</sup>. Participants were also advised of their rights to terminate the interview or take break from the interview for comfort.

The average length of interview was 55 minutes.

### **2.3.3 Interview Schedule**

Semi-structured interviews were conducted. This interview style enables specific questions to be asked while allowing for greater flexibility in following up responses to examine areas in greater depth. In constructing an interview schedule Smith (1995) advises questions should be neutral rather than leading or value or jargon-laden, and should be open-ended. Smith argues that using questions that are “too explicit” (page 15) may lead participants in a particular direction and close off the interview to possible novel or unexpected areas of discussion.

Smith (1995) encourages the interviewer to start with general questions which may be sufficient to encourage participants to talk freely about the topic. These questions are then followed up with more specific prompts to help clarify questions or help hesitant participants (Smith & Eatough, 2007). Typical prompts used in the interviews in this study included asking participants to talk more about or clarify a specific experience, feeling or event, and asking how a particular experience or event made them think or feel.

The following questions were asked to all participants:

1) Can you tell me about the time you were told of your husband/ wife’s dementia diagnosis?

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<sup>4</sup> Participants were informed that any comments they made would be anonymised. They were also informed that the researcher had an ethical obligation to break confidentiality if they (the participant) disclose that they, or another individual was being harmed, or at risk of being harmed by their own hand or by another person.

2) What has changed for you since your husband / wife received their dementia diagnosis?

These questions were asked to orientate participants to the subject area of interest, namely their experience of the diagnosis and the early stages of the dementia process in their spouse. The second question concerned the general impact of the diagnosis on their lives (See Appendix VI for Interview Guide).

## **2.4 Data Management**

All interviews were recorded using a digital voice recorder. The recordings were then transferred to computerised audio files, stored on a password protected computer. The recordings were then transcribed verbatim. At the point of transcription a code was assigned to each transcript and all personal identifiable information was removed.

NVIVO 8.0 software package was used to assist in the organisation and structuring of emergent themes.

## **2.5 Data Analysis**

The data was analysed in accordance with IPA procedure as set out by Smith (Smith & Osborn, 2003; Smith & Eatough, 2007, and Willig, 2001), as represented in Figure 2.

As discussed in section 2.1.1 the identification of themes involves an interaction between the researcher and the interview text. Throughout the analysis process the researcher attempts to stick close to what participants are saying however the emergence of the themes also draws heavily on the researcher's own interpretative resources. Thus the researcher is an integral part of the analysis process whereby themes are identified and labelled.

- 1) *Transcription stage*: During this stage, comments, thoughts, reflections and points of significance were noted in a reflective diary to consider in the context of later interpretations.
- 2) *Initial reading of the transcripts*: This stage involved reading the text and recording the researcher's reaction to the script. Following the initial reading the researcher continued to re-read the text and record thoughts, observations and questions in the left hand margin (commenting not only on content of text, but language style and contradictions in speech). Notes or coding was made on a line-by-line basis. This stage is important as it immerses the researcher in the participant's narrative. By re-reading the text, the researcher becomes increasingly familiar with the text and aids in the development of themes.
- 3) *Identifying and labelling themes*: The researcher continued to read the text, and used the notes made in the previous stage to identify themes which were recorded in the right hand margin. This stage used concepts which captured the essential quality of what is represented in the text. According to Smith and Eatough (2007) this stage may also include introducing psychological concepts to capture the meaning of the text.
- 4) *Linking themes and identifying thematic clusters*: This stage involved the researcher listing the themes which had been identified in the previous stage and beginning to make connections between these themes (referred to as clusters). The clusters were given labels which best captured their meaning. The researcher moved between reading the list of themes and re-reading the transcript in order to check that the clusters made sense in relation to the original transcript.
- 5) *Production of a summary table*: theme clusters, sub-themes (identified in stage 3), brief quotations and references to where the relevant extracts could be found in the transcript (See Appendix VII for an example).
- 6) *Repeat Steps 1 to 5*: For each participant with new themes coded as well as repeated ones, to identify similarities and differences between participants' accounts. New themes were checked against earlier accounts, to determine whether they were actually new themes, or merely new manifestations of earlier themes.
- 7) *Integration of cases*: Summary tables for each individual participant, were integrated into one list of master themes which represented the participant group as a whole (Appendix VIII). The master themes are checked with each participant.

Figure 2: Step-by-Step Analysis Procedure

Stages 1 to 3 of analysis were carried out manually with the researcher noting thoughts, reflections, low-level “descriptor” labels and sub-themes in the margins of the transcripts. These were then transferred into an NVIVO file which allowed quick retrieval of the data and organisation of sub-themes.

Stage 4 was facilitated using NVIVO. The use of NVIVO removed the need for physically cutting and pasting extracts to organise sub-themes and superordinate themes. NVIVO also allowed the researcher to record thoughts and make notes as memos as themes were identified and linked (See Appendix IX, a print-out from the NVIVO file which includes examples of “descriptor” labels, sub-themes and superordinate themes).

Stage 5: Based on the superordinate and sub-themes identified in stage 3 and organised using NVIVO in stage 4, summary tables were compiled manually for each individual participant (see Appendix VII). These tables listed whether a sub-theme was present and where a supporting extract could be found in the transcript. This allowed the researcher a means of evaluating (at a glance) the presence and depth of sub-themes across each participant transcript. These tables served to ensure an idiosyncratic level of analysis.

Stage 7: The summary tables for each participant were integrated into a master list of superordinate and sub-themes, demonstrating group level of analysis. This process was also carried out manually (See Appendix VIII).

## **2.6 Ethical Issues**

Before commencing the study, a research proposal was reviewed by the University of Edinburgh Course Organisational Group who were satisfied as to the experimental design, methodology and validity of the study.

Additionally ethical approval was sought from the local area Medical Research Ethics Committee in November 2007. A favourable opinion was granted in January

2008. The study was also submitted for approval and registration with the local Research and Development Department. This was granted in 2008 (See Appendices X and XI).

### **2.6.1 Autonomy and Obtaining Informed Consent**

According to Orb et al. (2001) the protection of participants' rights is as important in qualitative as quantitative research. This is honoured by ensuring informed consent is obtained from participants (Appendix V). In this study participants were provided with a Participant Information Sheet and given the opportunity to discuss the study with the researcher via telephone contact. Additionally a pre-interview meeting was arranged to provide participants with a full explanation of the study, covering all elements included on the Participant Information Sheet. This also gave participants the opportunity to clarify issues and discuss concerns with the researcher.

Orb et al. (2001) argue that informed consent is a dynamic process and should undergo regular renegotiation. All participants were advised of their right to withdraw at the pre-interview meeting and prior to interview commencement. However, due to the potentially distressing nature of issues raised during the interview, the researcher regularly checked whether participants wished to continue.

Orb et al. (2001) also emphasise that in some qualitative research questions may arise in determining who needs to give informed consent. In this study, participants were asked to reflect on the impact of their spouse's diagnosis, and thus it was questioned whether written consent should be obtained from the person with dementia. This issue was discussed with the local area Medical Research Ethics Committee who deemed this precaution unnecessary. Whilst written consent was not obtained, participants were informed that they could discuss their participation with their spouse and in all pre-interview meetings the spouse with dementia was also given the opportunity to discuss the study with the researcher.



### **2.6.1 Beneficence: Protecting Anonymity and Minimising Distress**

At the beginning of the study participants were informed of the limits of confidentiality and anonymity<sup>5</sup>. All personal identifiable information was removed or replaced at the stage of transcription and direct quotes in the final report were anonymous. The recordings were stored on a password protected computer and listened to only by the researcher.

Participants were also advised that issues may arise which they may find distressing and may wish to take a break or discontinue the interview. Participants were also informed that if they were experiencing more long-standing psychological difficulties or distress a referral to the appropriate service, could be arranged via their GP if they wished. The researcher also allowed a short period of time following completion of the interview to discuss this experience and any impact it had on the participant.

## **2.7 Ensuring Quality**

In research adopting a quantitative methodology, the quality or scientific value of that research is measured against standards of reliability, validity, objectivity and generalisability. However such criteria are not consistent with the philosophical paradigms on which qualitative research is grounded. Thus there have been attempts to develop criteria appropriate for methodological and analytic rigour in qualitative research (Elliott, et al., 1999, and Yardley, 2000).

### **2.7.1 Sensitivity to Context**

The researcher was mindful that participants were aware of her role as a trainee Clinical Psychologist which may have contributed to a reluctance to criticise individuals the participants perceived as the researcher's colleagues. Similarly,

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<sup>5</sup> See section 2.3.2

participants were aware that the research was carried out as part of a doctoral thesis, it is possible this may have contributed to a perceived power imbalance with the researcher perceived as having “expert” knowledge in this field. This may have contributed to participant concern about providing the “right” answer, with the goal of pleasing the researcher. Additionally, all the cohort beliefs of this particular generation must be considered (Laidlaw, et al., 2003). Participants within this generation may hold particular beliefs about expressing personal problems to a stranger or discussing aspects of the personal relationship they hold with their spouse. In recognition of a possible perceived power imbalance between the participants and the researcher, all participants were given the option of carrying out the interview in an environment they felt more comfortable including their home environment. Additionally, the researcher met with all participants prior to the interview with the goal of establishing a non-judgemental rapport and minimising any of the above concerns.

### **2.7.2 Commitment and Rigour**

The concept of commitment encompasses prolonged engagement with the topic and development of competency and skill in the methods used and immersion in the data. As well as carrying out a comprehensive literature review in the area of dementia diagnosis, the researcher has previously been involved in auditing a post-diagnosis support group for newly diagnosed dementia patients and their care-givers which was presented to the local Dementia Managed Clinical Network. In addition to extensive reading on the methods and principles of IPA, the researcher also attended an IPA training workshop which provided the opportunity to engage in IPA based interviews prior to commencing this research. Additionally, the researcher attended a seminar on using N-VIVO in coding and analysis. To further enhance commitment the researcher transcribed all interview content to allow her to become fully immersed in the data and also to aid in the reflection process.

Rigour in qualitative research, according to Yardley (2000) refers to “completeness of the data”. Rigour was enhanced in this study by interviewing as large a sample as

possible, considering the need for in-depth analysis and within study time constraints. Multiple coding was also used to enhance rigour (Barbour, 2001), with the clinical supervisor of the researcher provided with a random selection of transcript sections. Additionally, a copy of two full transcripts and emerging codes were reviewed by a researcher experienced in qualitative research and working with older people. This was to identify not just the degree of concordance between researchers but also to refine coding frames and furnish alternative interpretations (Barbour, 2001). Respondent validation (cross checking interim research findings with participants) was also used in this study. After analysis of the transcripts was complete, three participants were randomly selected and invited to meet with the researcher in a separate interview to provide feedback on the identified themes and discuss the findings. Finally, cyclical checking of themes against each transcript helped ensure that themes were generated from the data itself.

### **2.7.3 Transparency and Coherence**

Transparency (the degree to which all relevant aspects of the research procedure are disclosed) was enhanced by providing a detailed description of how the data was collected and analysed. The use of N-VIVO software also facilitated this process by allowing a clear data trail. The researcher also kept a reflective diary throughout each stage of the study.

Coherence was also maintained by allowing the researcher's clinical supervisor to check sections of the transcripts and coding process to assess the degree to which the findings "fit" with the theoretical background to the study and the research questions.

### **2.7.4 Impact and Importance**

Yardley (2000) cites this as the "decisive criterion" by which any research must be judged; the impact the research is likely to have on understanding of an area and its translation into practice. It was anticipated this research which highlights the experiences of carers during the diagnosis and post-diagnosis stage of dementia care,

may offer insights to those professionals who have continued contact with patients and their carers. This may hopefully have implications for ongoing care, possibly by creating more positive and supportive interactions with care-givers at this stage.

### 3. FINDINGS

#### 3.1 Distribution of Themes

16 key themes emerged from the interviews and these were subsumed within five superordinate themes: *Getting an Answer* (“You just need to put a name to it”); *Losses and Changes for Self*; *Changes in the Marital Relationship (Threats to Coupledness)*; *Limiting the Emotional Impact of the Diagnosis*, and *Preserving Normality*.

All superordinate themes emerged from the narratives of all participants<sup>6</sup>. Although there were greater differences in their presence and depth of discussion, all sub-themes appeared in at least half of the participant narratives.

Participants P01, P03, P04 and P05 spent greater time talking about their experiences and covered a greater spread of sub-themes, often in richer depth. Participant P06 covered the fewest number of sub-themes which may be reflective of the recency of the disclosure of her husband’s diagnosis, thus giving her less time to reflect on the diagnosis.

These differences in representation of sub- themes will be referred to in the following section, in which each superordinate theme will be introduced, and its sub-themes will be presented along with illustrative verbatim quotations from participant transcripts.

See Appendix VIII for a summary table of themes featured in individual participant’s accounts.

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<sup>6</sup> All participants are referred to by their Participant Identification Number (PIN).

## 3.2 Themes

### 3.2.1 Getting an Answer (“You just need to get a name put to it”)

All participants described the diagnostic disclosure as something that was actively sought or needed. The importance of gaining a diagnostic label for their spouse was present in all narratives. This superordinate theme was spoken in rich detail by some participants.

#### 3.2.1.1 Confirming Suspicions and Unanswered Concerns

All participants described a process of recognising changes in their spouse and beginning to make attributions for these changes including temporary physical and psychological causes. Participants discussed how possible causes for the changes were slowly eliminated and a subsequent realisation of the possibility of dementia as an explanation. Thus the diagnosis appeared to be a formal recognition of what participants had begun to recognise themselves;

Extract 1: P04; Lines 85-94

*I: You said that you “took it alright” when you heard the diagnosis, would it be ok for you to tell me more about that time?*

P04: Well, I mean, it was not too unexpected for me, I couldn’t think what else was happening because we’d corrected the other things. It was just a year after we’d lost [daughter] (...) We were just a year past that and the cataracts had been done and the hearing aid was got and still it was not right, because to start with...well, if you’re not hearing well or seeing well, life cannae be great you know, so we got all that done pretty smartly. I was aware of all that. And still things weren’t right so you knew it was something else (...) like I said.

Some participants talked about experiencing relief in getting an answer because it meant an end to a sometimes lengthy and frustrating quest, as their spouse displayed further symptoms which could no longer be understood by initial explanations;

Extract 2: P07; Lines 66-73

*I: Going back to the time when you heard the diagnosis can you tell me what that time was like for you?*

P07: Umm (...) well (...) you know it wasn’t as I said Alzheimer’s. But another type of dementia and the doctor told us her memory would get worse over time

(...) you know (...) it wouldn't get any better. It wasn't such a surprise you know 'cause I had noticed things getting worse. It was good in a way to know what was wrong. 'Cause as I said, I knew it wasn't worry, I knew it wasn't angina so I knew something was wrong. So it was good to know what was wrong, 'cause I knew something was.

Many participants discussed how their suspicion of a dementia condition in their spouse was influenced by prior experiences of caring for someone else diagnosed with dementia or from media exposure. As a result of such knowledge, participants had a greater understanding of the symptoms and what to expect;

Extract 3: P08; Lines 34-40

*I: And as you said you were not shocked? Was there anything else you felt or thought when you heard the diagnosis?*

P08: Well, I just accepted it you know (...) There was no difficulty for me in accepting it. No I honestly have to say, because I could see it coming, because we've had it before (...) maybe if we hadn't had it before with his sister, I might not have but the signs were there.

### **3.2.1.2 Validation and Recognition of Concerns**

Many participants described an initial sense of relief in obtaining a diagnosis for their spouse as it represented an official acknowledgement by others of the changes they had noticed in their spouse.

Many participants' narratives detailed experiences of having their initial concerns ignored or minimised by health care professionals. Participants talked of feeling isolated and unsupported at this time.

Extract 4: P01; Lines 116-131

*I: Are you alright to tell me more about these visits to your doctor? What it was like for you?*

P01: Umm (...) well...umm, you see it's difficult (...) but you just go, I suppose (...) ((laughs)) (...) I suppose I would have liked the doctor's attitude (...) ((laughs)) (...) when he didn't turn up to the appointment (...) ((laughs)) (...) to be different 'cause I thought it was a bit harsh. [Participant's husband had refused to attend his previous appointment]. You see (6) I find with GP's (...) I found this with my younger son, and again now, you take them along for an appointment, for an ailment or another and they only see a person for a few minutes or if they come to the house they are only in the house for a few minutes and (...) they just assume that everything sails along. They don't see the difficulties that are going on. Doctors, GPs, don't see what is going on, they maybe think that things are difficult with patients with these conditions but they don't live with it, they don't realize...they don't have a clue.

Participants' descriptions of these experiences, speak of their wish to be acknowledged and have their concerns listened to and legitimised, and frustration when this does not occur.

Extract 5: P03; Lines 5-12

*I: Ok, so I would like to begin by asking you to think back to the time of your husband's dementia diagnosis?*

P03: I think when we heard it were more relief than anything, 'cause we've know for years something wasn't right. See, it's been a gradual progression you know and I mean you just know just to get a name put to it you know. 'Cause doctors tend to look at you a bit stupid when you say at first. Well you know but you don't know what it is but now you know. It covers such a mass area (...) umm (...) covers everything when they say "You've got dementia" and it explains things and you know. But like when you don't know, they look at you like you're making it all up but now it's actually been diagnosed and given a name then (...) "Oh yes, that's fine".

A small number of participants described welcoming the diagnosis as their early concerns were not shared and, in some case, rejected by family members including their spouse. Linked to *Practical Utility of Diagnostic Label*, participants acknowledged that formal disclosure of a diagnosis often initiated increased support from family members and friends who they felt previously did not recognise the seriousness of the situation;

Extract 6: P05; Lines 393-398

P05: Actually, you asked about my reaction when we got the diagnosis and what I should have said was relief because you can then tell people (...) sad as it was and I knew in myself there was something going on in his head but that is really what I should have said (...) 'Cause it's got me support, 'cause my sister, my younger sister especially, she always said, "I never saw anything wrong with him".

### **3.2.1.3 Practical Utility of Diagnostic Label**

Whilst discussing a growing suspicion that their spouse could have a dementia condition, many participants spoke of their recognition of the importance of a diagnostic label. Generally, this theme was discussed in less depth than other sub-themes.

Many participants acknowledged that the confirmation of a diagnosis opening doors for their spouse. Of particular concern was that, where applicable, their spouse would



be able to access medication which may potentially slow the progress of the condition. Consequently, participants' narratives convey feelings of urgency and frustration at delays;

Extract 7: P04; Lines 50-54

I was very grateful we were in Scotland and I knew if there were treatment at all that he should have (...) here is where we would get it. I was aware that they didn't get it in England and that made me more determined that he was diagnosed early. I was also aware that the treatment could halt things in its tracks as opposed to repair and so I thought the sooner we get it the better

A smaller number of participants recognised that a diagnosis facilitated support for themselves and that prior to this official confirmation they were coping with changes on their own;

Extract 8: P03; Lines 72-79

*I: Ah I see, so you've talked about the changes for [husband] following the diagnosis, were there any changes for you at this stage?*

P03: I suppose I got a bit more support with [Early Stage Dementia Co-ordinator] (...) she's nice (...) umm, she's starting up a day centre locally so I've got a few hours break but now he's been diagnosed I can get that help whereas before it was just me and [husband] (...) and so that has changed and I have to say has been a huge, huge help for me.

The utility of a diagnostic label in planning for the future was also discussed in some narratives, with participants recognising that a diagnosis would allow for financial support and the option of respite care;

Extract 9: P07; Lines 160-164

*I: So it sounds like you've prepared for the future.*

P07: Yes, yes, I suppose that has been what is good about knowing what this is (...) It has meant we've had a wee bit extra support (...) because when [Early Stage Dementia Coordinator] comes we put through for a wee bit extra every month now [referring to financial aid for carers].

#### **3.2.1.4 Contradictions and Ambivalence towards Getting a Diagnosis**

Although all participants described a process of searching for a diagnosis for their spouse, the narratives of some participants also indicate a degree of ambivalence towards the diagnostic label once obtained. This suggests that contradictory views

can be simultaneously held by an individual towards the need for a diagnosis. The utility of a dementia diagnosis is questioned as participants acknowledged that whilst medications may slow the degenerative process, there is ultimately no cure or way to stop or reverse it;

Extract 10: P01: Lines 202-210

P01: I think it helped, getting a diagnosis, in the respect that we did get a diagnosis (...) ((laughs)) (...) but it wasn't helpful as well 'cause I know there isn't a cure. I feel a great sadness, 'cause I know it's going to be a long hard slog (...) umm (...)

*I: You said, it "helped" getting a diagnosis, is there anything else that helped at that time, or can you tell me more about what you mean?*

P01: Umm (...) well there is nothing that could have happened to make it better. What could people say to you to make it better? They can't.

Additionally, some participants distinguished between the practical need for a diagnosis and the emotional impact when this is disclosed, as indicated in the following excerpt, there is a distinction between *needing* a diagnostic label and *wanting* one;

Extract 11: P02: Lines 90-97

P02: I think that's just a reaction to the diagnosis, it just kind of left me numb.

*I: Numb?*

P02: Yes, for a while, it wasn't a shock really because I had already been thinking that it was that (...) you know dementia or Alzheimer's. But it doesn't make it any less sad you know when you hear

A small number of participants argued that while a diagnosis may provide access to support services, these are often not required at this stage in their spouse's condition, and therefore a diagnosis has no immediate benefit. In these cases, the perceived limits of the support currently available, participants spoke of feeling hopeless about the situation. P05 talked of how she sees this post diagnostic period as almost a time of limbo, waiting for further changes in her husband's condition, but believing nothing can be done to prevent these or alter the situation;

Extract 12: P05: Lines 131-133

P05 (...) at the stage it's at just now I know there is nothing that can be done 'cause he's not ready for day-care and he's not ready for respite

Thus for some participants, the sought after diagnosis, did not bring much in the way of change at this stage.

### 3.2.2 Losses and Changes for Self

The superordinate theme *Losses and Changes for Self* was present across all narratives, however there were differences in the presence and richness of sub-themes. The sub-theme *Growing Sense of Restricted Freedom* emerged across all narratives and discussed throughout accounts. The second sub-theme, *Loss of Expectations and Futures* was represented across most accounts and in particularly rich detail in the narratives of P01, P02, P05 and P06. Whilst the third sub-theme, *Grieving for Prior Life* was referred to across many accounts, a smaller number of narratives made specific references to the “ending” or “loss” of their own life or prior world.

#### 3.2.2.1 Growing Sense of Restricted Freedom

The sub-theme of *Growing Sense of Restricted Freedom* was present in the narratives of all participants. All participants made reference to altering or restricting their plans or daily activities to prevent leaving their spouse alone for significant periods of time. P03 described a lack of spontaneity associated with even relatively mundane tasks such as going shopping;

Extract 13: P03: Lines 99-102

P03 What has changed? Hmm (...) Well I can't just jump in the car and go shopping. I have to take him with me...if he'll go...If he doesn't want to go I have to wait until there's a football match on the telly he'll want to watch and then I know I've got a certain time. But I'm not free (...) I can't do what I want when I want and that's hard.

All participants discussed how decisions about activities and control over how they conduct their lives are now determined by their spouse's needs. This restriction in self-determination and autonomy is reflected in the following excerpt, whilst P05 refers to getting back from outings when she “wants” to, the tone of the passage and her reported frustration suggests such decisions are not completely her choice;

Extract 14: P05; Lines 266-279

P05 One thing I do find is when I go out I'm always thinking about having to get back and I tend to do things by myself now rather than with friends so I know I

can get back at the time I want to get back at you know (...) to make sure things are alright you know (...)

*I: Umm and how does that make you feel, having to do that instead?*

P05 Uh it annoys me and frustrates me sometimes 'cause I feel I could be away for a whole day, enjoy my lunch hour and get back when I feel like doing it 'cause I used to do that (...) I would just leave his evening meal and he was quite happy to heat it up in the microwave or whatever he uh (...) and knew he'd be ok and he'd go out and do his own thing after he'd had it but that's all changed, that frustrates me a bit now 'cause I can't do that.

This extract highlights how even when P05 does the same activities, the quality of these experiences has changed as she has to think and plan ahead. As well as describing specific instances of restricting activities and choices, several participants made reference to a more general sense of restricted freedom in their perception of the role they are in the process of adopting. Indeed, the frequent use of phrases such as “escape”, “no way back” throughout a number of narratives is suggestive of this sense of restriction and inevitability of what their lives will now entail. As demonstrated in this extract from P01's narrative, she reflects on how there is no “exit” from the caring activities or duties she has taken on.

Extract 15: P01: Lines 327-33

P01 You know I said to him about a week and a half ago, I said to him something about (...) uh (...) having to do things and he said, “I don't have to do things. I'm retired”, and I said, “Yes, and so am I”. He says, “I worked for 50 years, I don't need to do anything now”, and I said, “Why do I have to keep doing things? I retired as well”. I said, “When am I going to be able to stop?” And he said, “When you are dead” (...) ((Laughs)) (...)

This extract from P01 also highlights a feature of a number of accounts, when participants discuss experienced losses and changes; a comparison is often made with their spouse. Some participants reflect how their spouse has experienced losses also but reason that these differ to their own as their spouse is not “aware” or does not seem to care, as P01 remarks;

Extract 16: P01: 270-272

As I said to the doctor the other day, my life has narrowed right down and he said, “Yes but so has your husband's” and I said, “Yes, but my husband doesn't care about his life narrowing down”.

For many, this limited freedom is associated with heightened frustration and, in a number of cases, sadness at the possibility of growing restrictions in the future as their spouse's condition changes.

### 3.2.2.2 Loss of Expectations and Futures

The majority of participants reported a loss of their anticipated futures. These participants made references to an inability to continue with their plans for the future as they are aware that their spouse's condition may change. The following extract highlights a certainty of loss as P06 described how it "will be the last time" she goes on holiday with her husband, despite her acknowledgement that her husband's condition has not deteriorated significantly. This exemplifies a belief across many narratives that future losses for participants and their spouses are inevitable,

Extract 17: P06: 226-231

P06: I don't think too much about the future and what will happen but sometimes you can't help it. I mean we have always gone on holiday to America, well for the past couple of years we have gone to Florida, and we love that, and we had planed to go this year, later on in September. And we probably will but it is (...) Well, it will be the last time we do it. He is good now and it is so recent that we got the diagnosis it will not be a problem, but you have to think that this time next year we will not be able to do it.

The narratives of some participants suggest a sense of dissonance between their expectations for the future or for their retirement and the reality of what their lives may now hold. For participants P02 and P05 previously held hopes for their retirement had sustained them through stressful times. Both participants discussed how their husbands had been "workaholics" and they had accepted or tolerated this, believing their retirement would herald a new and more relaxed chapter to their lives;

Extract 18: P02: Lines 80-90

*I: We were talking about the time that you heard the diagnosis(...)*

P02: Yes, I was thinking, "Why is this happening to us?" I felt an awful sadness 'cause he was coming up for his retirement and he was a workaholic for the time we were married (...) "Oh no, I can't do that, no I can't go there, no I'm working". Well that's all very well but what's the saying (...) "Make Jack a dull

boy” and I thought well it’s for our own good that he’s working so you just put up with it but it was sad. I felt sad, he was coming to the end of his working days and he got diagnosed with this. I thought we would’ve had more time to go away on trips and (4) and just enjoy our retirement. (Lines Suppressed) I thought he would be more relaxed and I would be more relaxed. But that is gone now, what I thought is gone.

Indeed, as P05 conveys, it is not only definite plans or a usual way of life, but also possibilities and potential options that are lost;

Extract 19: P05: Lines 211-218

*I: How does it make you feel talking about these things?*

P05: No (...) I get emotional when I’m speaking about some things (...) I haven’t had a lot of holidays and we don’t go out for meals, we don’t go away for day trips so in a way I’m not missing that. I haven’t had to adjust in that way that some people will have to (...) You know those who have always done these things (...) gone out for meals, gone out dancing. I’ll not miss that side of it (...) those as soon as you can’t get a thing you want it right enough. It’s just that it will never happen now (...) .that it isn’t going to (...) and that is hard.

For the majority of participants this sense of a loss of expectations or a diminishing future is accompanied by sadness, however for a smaller number, the loss of “what might have been” is linked to feelings of injustice or unfairness as they believe the anticipated rewards of retirement have been denied to them, as P02 said (See Extract 17) “*Why is this happening to us?*”

### **3.2.2.3 Grieving for Prior Life**

Reference to a previous world or life was present in some participant accounts, with descriptions of previously or currently held roles or involvement in social and leisure activities. However for a minority of participants there is a clear sense of grieving or bereavement for their previous lives or roles; an awareness that their world is changing. In some cases this is discussed in terms of a slow process (related to the above sub-theme of restricted freedom) whereby their world and are social roles are gradually narrowed and lost to them. P04 talks of how she is gradually stopping leisure activities or reducing the frequency of these activities. She describes it as “bringing her life in” as if by restricting or ceasing these activities her world is slowly collapsing in;

Extract 20: P04: Lines 162-165

P04: I'd stop my walking instead and I've stopped my country dancing because it was just a night I went country dancing (Lines suppressed) So gradually, I'm just bringing my life in basically. All the things I do are changing.

For a subsection of these participants this process is more sudden and outside their control. For P01 although she speaks of slowly making changes to her routine, the actual confirmation of the disclosure of a dementia diagnosis represented the sudden end to her old life;

Extract 21: P01: Lines 465-469

P01: Mm (...) well (...) in a way but also when it happened (...) when we got the diagnosis (...) It was only then that I did really realise that my life was over so to speak. I feel now that my life is over. I mean, I'm still carrying on the carer role, I'm still doing the things that I've always done, housework, caring for my sons, and now caring for my husband (...) It's just, I feel my life is over.

The above extract highlights how P01 views her role as a carer as something she must do, listing it together with household chores, the tone of this excerpt implies almost carrying on automatically, a sense of existing but no longer *living*. The sense of loss for themselves is more widely reflected in the language used by most participants in their discussion of changes they anticipate in their leisure activities and social world. The adoption of past tense and frequent use of words such as “never again”, “gone” and “the last time” suggests a sense of finality and ending. Similarly, in a small number of participants their sadness at discussing these losses was evident as they became visibly tearful.

### **3.2.3 Changes in Marital Relationship (Threats to Coupledness)**

This superordinate theme appeared to be represented in some weight with participants, emerging across all narratives and frequently discussed in rich detail. The theme of *Anticipated Loss of Affection and Reciprocity within Relationship* was the least well represented. However, this sub- theme still appeared in more than half of the transcripts.

### 3.2.3.1 Acknowledging Changes in their Spouse

All participants described changes in their spouses, focusing in rich and extensive detail on changes in memory and temperament. All participants discussed how these changes impact on their spouse's participation in previously held roles such as social or leisure activities, and also in the contributions they make in the home. Since the diagnosis disclosure small changes and mundane forgetfulness in their spouse now takes on a new meaning and are now symbolic of wider changes in the person of their spouse, a theme which was common across narratives;

Extract 22: P08: Lines 88-94

P08: See he tidies up every night after we've eaten. He'll fill the dishwasher and tidy the kitchen so I just let him do all the things he's normally done but some nights he'll come through and he'll sit down and I'll go back and it's not switched on or there's a couple of times it's only half filled and he's gone away and left it, it's obvious he's gone off to do something else and he's forgotten it. I know that is only a small thing, but it reminds me...just reminds me of how he is changing (...) and not (...) although he tries to do the same things, he is not the same.

Similarly, a number of participants make reference to their growing concern that the beginning of changes in their spouse has implications for their spouse's role within the wider family as a father, mother or grandparent;

Extract 23: P01: Lines 411-414

P01: My other sons (...) well, our youngest (...) if he wants something he'll go to his dad. This is one of the saddest things, his dad is the one who'll get him ready, he'll come and get his dad if something goes wrong. His dad is his hero but I can see this is going to slip away also.

A common theme across narratives is participants' concern that changes and losses in their spouse will accumulate over time as their spouse's condition deteriorates. As exemplified in the following excerpt from P04, these anticipated losses go beyond specific changes in memory and what they can or cannot do but the loss of the entire person of their spouse, losing "him" bit by bit;

Extract 24: P04: Lines 229-232

P04: The most difficult part is knowing that I'm going to lose him bit by bit. It's just so difficult in many ways because I don't know (...) since we've retired we just kind of do (sharings) and I know that that can't happen for very much longer and when I see this past week for instance how many things have gone.



These changes in their spouse are associated with heightened frustration in some narratives as they recount mistakes made by their spouse or things they have forgotten. However, participants P01, P04 and P08 also reported an overwhelming sense of sadness as they anticipate future changes in their spouses and, although in the early stages of the condition, experience almost a pre-emptive grieving for the loss of their spouse.

### **3.2.3.2 Shifting Dynamics and Status within the Relationship**

Across all narratives, a shift in the dynamics of the marital relationship was an emergent theme, with all participants giving richly detailed descriptions of changes in their status within the relationship. Participants mostly described a two-fold process in which their spouse was gradually becoming more dependent on them and in turn they were becoming more protective of their spouse.

Many participants reported becoming more vigilant towards their spouse following their diagnosis related to a concern that their cognitive status puts them at risk of harm;

Extract 25: P07: Lines 78-83

P07: Well, I have to be alert all the time (...) if I feel her moving about in bed (...) I'm a light sleeper...but she'll go (...) I'll say, "Where are you going?" And she'll say, "I'm going to the toilet". She was a wee bit of a problem with her...what you women have (...) and I'll say, "You've just come back from the toilet" (...) "Naw I haven't", she'll say. I don't sleep, I've never been a sound sleeper but I have to be in alert in case anything happens.

The shift in relationship dynamics is portrayed in many participants' accounts as a move from a more equal sharing of marital roles and responsibilities to adopting a more parental stance as they, in effect, recognise becoming a carer. P03 talked about how her decision to give up smoking is linked to the responsibility she feels towards her husband and how she has to stay well in order to care for him, his needs are now prioritised;

Extract 26: P03: Lines 79-87

P03: ... Where I go, he has to go it's just like having a child.

*I: Like having a child?*

P03: Mm hmm, yes, well you can't leave him for so long (...) And (...) You see I tried to stop smoking during Christmas and New Year but something just snapped and I started again. I went to get help to see about stopping smoking and they said, "Why? After all these years?" And I said I'm going to have to start looking after myself 'cause I've got him to look after.

A small number of participants also discussed becoming more protective of their spouse, not only in terms of physical safety and well-being, but in protecting them against emotional distress following the diagnosis disclosure and cushioning their spouse from the impact of additional losses of independence. In the following excerpt P04 talks about the importance of maintaining "normality" for her husband (see also Extract 51);

Extract 27: P04: Lines 222-227

P04: See if he said before, "Shall we go somewhere?" and it was a winter day, I'd say, "Aww let's not bother", 'cause it was a winter day and it was cold but now (...) See now [husband] doesn't drive, so like today we are going to go somewhere, I don't know where, but I feel I must do that for him now he's not driving. I wouldn't say, "I couldn't be bothered" because it wouldn't be fair because at least before he could have gone himself. I would do that.

The language used by P04 also reflects the sense of duty which emerged across accounts when discussing their relationship with their spouse, that protecting or assisting their spouse is something they "have to" or "must" do.

Some participants expressed a level of frustration with this shift in roles and responsibilities within their marital relationship, and for many this sub-theme is closely related to the sub- theme of restricted freedom as participants become aware of their spouse's growing dependency.

However as a contrast, P05 described how these changes have provided her with an additional sense of purpose as she takes on the responsibilities that were previously

her husband's. The following excerpt implies a sense of personal growth associated with facing new tasks and challenges;

Extract 28: P05: Lines 407-410

P05: The other thing is it's (the diagnosis) sort of given me a bit of a lift because I now have to do everything financial and see to all those things (...) something I could have done before but I was never allowed to do but now I'm doing them all and I think that's given me a lift in a way because I've got a purpose.

However, she was the only participant who identified positive aspects of these post diagnostic changes in relationship dynamics.

### **3.2.3.3 Anticipated Loss of Affection and Reciprocity within Relationship**

Many participants discussed changes in displays of affection or intimate exchange. For some, this is represented in a loss in the physical or sexual side of the relationship and in shared experiences such as socialising as a couple;

Extract 29: P06: Lines 212-214

I was quite sad about that in the first place 'cause I would have quite happily have gone on with a sex life had it been there.

However, for the majority of participants the loss of closeness in their marital relationship is, at this stage, anticipated rather than actual. P04 talks about how she anticipates the day when her husband may no longer act the role of the protector or chivalrous gentleman. What P04 finds difficult is not about the act of carrying shopping bags but rather that it represents no longer having someone look out for her needs, instead she will be the one who is doing the looking after;

Extract 30: P04: Lines 239-248

*I: When you said, "it's such a shame" and you were talking about feeling sad about the changes that are happening, can you tell me what kind of changes you mean?*

P04: There is also (...) I suppose there is a sadness that I'll not be looked out for 'cause always just opened doors or said, "Look, I'll get that; that's heavy", and I know I'll stop hearing that (...) I'll be the one doing all the looking out and I

won't hear him doing his little things. At the moment he still does and I let him.  
I'm not worried about it. I can lift a heavy bag or one of the girls will do it (...)  
but I'm just sad, I won't be looked out for.

As they adopt a caring and protective stance towards their spouse, some participants described an awareness this may not be reciprocated in the future. Some participants anticipated the loss of the romantic idea of a spouse; “the one who loves you” in romantic sense, and fear they will no longer be remembered in that way. This is most poignantly encapsulated in the following excerpt as P01. P01 discussed in rich detail how she finds comfort in her husband's displays of affection and appreciation. Despite this acknowledgement of the loving and affectionate relationship she shares with her husband, P01 goes on to talk about how she fears the loss of these future displays of romantic love and appreciation by her husband. Her saving of previous cards is her attempt to “treasure” what she fears will be lost to her in the future;

Extract 31: P01: Lines 379-387

P01: I think our Golden Wedding Anniversary at the beginning of next month, I'm not even (...) I can't think (...) it's like a non-event. I mean I know it's a huge milestone but in a way that's disappointing because I thought we could go to Australia, we could do that, that would be our Golden Wedding thing, you know (...) and I know I won't get a card, I know I won't get anything. I'm not bothered about getting anything, it's just like, like a symbol really 'cause he's always bought me the most beautiful cards, beautiful words in the cards. Unfortunately, I haven't kept them, well I've kept the Christmas ones and I've kept my last birthday one 'cause I know it's probably going to be the last one, so I'll treasure them.

Participants talked about how anticipated losses are different than difficulties experienced before within their marital relationship and thus present a unique challenge for both partners to adjust to;

Extract 32: P02: Lines 123-124

P02: I find that we've drifted apart. We used to have rows and everything but this is a different set up altogether.

### 3.2.4 Limiting the Emotional Impact of Diagnosis

All participants discussed various strategies they adopted to lessen the emotional impact of their spouses' diagnosis. This superordinate theme was represented in moderate depth, with all participants discussing more than one of the following strategies or approaches in the course of the interview. Participants P03 and P08 spoke of using all of the following strategies.

#### 3.2.4.1 Cognitive Avoidance

All participants referred frequently to avoiding thinking about aspects of their spouse's diagnosis. This appears to serve as a protective strategy adopted by all participants as they acknowledged thinking about the inevitable outcome of a dementia diagnosis, namely the deterioration of their spouse's condition, is particularly distressing;

Extract 33: P06: Lines 209-223

P06: But I would say I try not to think too much about things. Most nights when I get into bed (Lines suppressed) before I go to sleep and in that space of time I'll think about how long ahead before things can get worse and what that'll be like but other than that, I don't think, no I don't think about it much during the day. (Lines Suppressed) I would think if I did sit down and think about it we'd just stagnate really, so I don't (...) I don't think about it if I can.

*I: Stagnate? Can you tell me what you mean by that?*

P06: Well, I think if you think too much about it, it would be too upsetting what might happen (...) to him (...) 'cause you don't know really, no one does and it would be too sad if you did.

The above excerpt suggests the function of cognitive avoidance may be to allow participants and their spouses to maintain some sense of normality and not become overwhelmed by or "stagnate" in the emotional impact of the diagnosis. Other participants also talked about using cognitive avoidance as a way of limiting negative emotional reactions.

Additionally, a small number of participants acknowledged that thinking about the future is a futile exercise in the case of a dementia diagnosis as the course of the condition differs across individuals;

Extract 34: P08: Lines 131-143

*I: So you say you are trying to just enjoy your life now, and you try not to think about what this means?*

P08: Yes, because I don't want to see him getting like his sister 'cause that was awful (...) it was awful for him. When I first heard the diagnosis, that is what I thought of, how quickly will it become like that, how quickly will he change? I remembered her and I was very worried that it would be like that quickly for us. And I did ask [Early Stage Dementia Coordinator] what is the likely way it will progress? She did say that everybody is different, there is one lady who hasn't changed in 10 years so hopefully he'll be like that. I think (...) you know (...) because we don't know, I try not to think of what it will be like because you don't know.

Although all participants stated they try not to think about the future or “the big picture”, these claims stand in direct and obvious contrast to the content of their narratives. All participants discussed in rich and extensive detail the changes they have noticed in their spouses and in themselves, and make frequent references to anticipated losses, suggesting that attempts to block out “what may be” is not always successful or that suppression of such thoughts may only be possible temporarily;

Extract 35: P03: Lines 258-260

P03: As I say (...) I don't think an awful lot about myself, really, I don't think about what I'm missing or what I'm not gonna be able to do uh (...) most of the time I don't but there are times I think, “Oh God, I'm not gonna be able to have a whole day away”.

### **3.2.4.2 Making Downward Social Comparisons**

Many participants made downward social comparisons throughout their narratives to those who, for a variety of reasons, are perceived as worse off. This type of social comparison may serve as a protective strategy, helping to limit the emotional impact of a diagnosis and the losses participants attach to this;

Extract 36: P05: Lines 175-178

P05: I would never (...) I don't think I would ever go into depression because of it (...) I can always think of something (...) and I can always think of something and I can always think there are some people who are an awful lot worse than me.

P01 in making comparisons to others who she believes are in more difficult situations is able to identify aspects of her life which she is thankful for and views herself as fortunate;

Extract 37: P01: Lines 429-437

P01: I certainly don't want to be sorry for myself and I don't want people to be sorry for me (...) umm (...) because as I say (...) people have gone through an awful lot worse. I am happy I am living in this country we have quite a reasonable standard of living in this country. We have quite a reasonable NHS ((Laughs)) I use that term loosely, but we have a reasonable standard of life. We are not wealthy, but we eat well and we are warm and clean. I'd rather be here than sitting in Baghdad, I can tell you, or any of the other countries where there's so much deprivation. You only have to look at the television. When I look at that I think how lucky I am.

As well as making more general downward comparisons to various groups in society, P01 also made more self-relevant comparisons, by positively contrasting her caring experiences or situation with those who she believes would not cope or adjust as well. P01 also cares for her two adult sons. She acknowledges earlier in the interview that whilst this may present her with added "burden", this experience has allowed her to develop coping skills. She believes this gives her an advantage over other carers whose spouse has been diagnosed with dementia;

Extract 38: P01: Lines 439-444

I suppose, people just have to find their own way around the situation (...) As I say, I know I keep going on about being a carer for my sons for so many years (...) but (...) and (...) I do think (...) this in a lot of ways has helped me, it has helped, it has helped me, but I would think that for somebody coming into this, you know caring for a husband or wife...who has never been a carer it must be very, very difficult.

Other individuals make these comparisons to other carers, identifying personal attributes or prior experiences which have provided them with skills which they believe gives them an advantage. P07 talks about how as a couple he and his wife previously shared tasks and therefore he is not faced with coping with completely new responsibilities and learning new skills;

Extract 39: P07: Lines 201-207

*I: How does that make you feel? What do you think at times like that?*

P07: Well, now it could be worse (...) it's not so bad. It could be a different story if it were a man, you see, because a lot of women couldn't cope with these things. Now we work together for a lot of things, now our neighbour she lost her husband and she has all the paperwork and she can't cope.

In making such comparisons, these participants said they feel they are better able to cope with or manage future changes.

### 3.2.4.3 Focusing on “the Positives”

Many participants made references to the positive aspects of their lives and their relationship, and as demonstrated in the extracts below, this appears to be viewed by participants as a means of coping with their spouse’s diagnosis and the changes this has brought;

Extract 40: P08: Lines 115-129

*I: You talked earlier about being reminded of how [husband] is not the same, can you tell me more of what that means for you? Um how it feels to talk about that?*

P08: It is sad in a way, to think about what it means (...) I try not to. But I know I do more for him now and he does less, less and less everyday probably. But I try and keep things as normal as possible (...) I think that is in my nature to get up in the morning and make the best of everything. (Lines suppressed) I try that with the family too, one of my daughters used to always say, “I can’t find my “Pollyanna” today (...) I can’t find the bright side”. That has always been me, try and look to the positive ((laughs)). See he’s had his three score year and ten, he’s had a heart attack, and he’s got through all that. He’s got a very, very good quality of life, well we both have really. So this hopefully we will stay this way as long as possible.

By focusing on “the positives”, some participants strive to live in the present, thus preventing the focus from being on the future which represents further losses and change. For P04, focusing on the positives often involved reflecting on the things which have remained constant or unchanged in her life and relationship with her husband. She also discussed how she is glad she is able to continue with shared activities with her husband;

Extract 41: P04: Lines 343-347

P04: I suppose, if you make the best of everyday (...) who knows (...) who knows if there is a day you’ll fall under a bus and you can’t look to the future too much and I be glad of today. I be glad to (...) well I’m glad we were across the beach this morning and I’m glad we went for a swim and I’m glad we’re sitting here and [husband] is in the house doing what he likes.

Other participants also look to positives within their past. In the following excerpt, P03 discusses the benefits of revisiting past positive experiences within their relationship. Focusing on a shared and valued history, may possibly act as a reminder of how a marriage is built on more than a diagnosis and caregiving acts;



Extract 42: P03: Lines 156-161

*I: So how does your daughter help?*

P03: Well she'll be going on about things we used to do when they were little. But he can remember that so he'll enjoy that. I try to make him remember those times and help him keep busy...it helps him too. [Husband] and I still have a good laugh, both of us do (...) some of the things we do.

### 3.2.4.4 Distinguishing between Spouse and Condition

Many participants described making distinctions between their spouse and the condition particularly with reference to changes they find upsetting or frustrating;

Extract 43: P01: Lines 356-359

P01: I have to keep reminding myself that I have to be patient because sometimes I do get annoyed, I get fed up answering the same questions and I have to gear myself up and say, "He can't help it, it's part of the condition, he can't help it, he didn't ask for it".

The acknowledgement that upsetting behaviours in their spouse are not intentional acts but something out-with their spouse's control is related to the psychological concept of cognitive reappraisal and may allow these participants to protect closeness their relationship with their spouse, by directing their frustrations and hurt at "the condition" as if some external agency, rather than their spouse;

Extract 44: P02: Lines 170-172

P02: I don't think [husband] realises how much this has hurt me, how much (...) just the tone of voice and different attitudes, I suppose it's all to do with the condition really.

As P07 talked about how he attributes symptoms such as repetitive questioning by his wife to "this dementia" and how this helps limit the frustration he feels towards her. In the same excerpt he goes on to talk about how he met his wife and difficult times his wife previously experienced, thus recalling his wife separate to the symptoms she is currently displaying;

Extract 45: P07: Lines 146-152

P07: So I sometimes get frustrated but I've a good sense of humour so I just let it go and move on to another subject you know. I try not to get annoyed. I don't shout at her or nothing (...) she's been through a lot in her life, I mean (4). See after her husband died, she was really quite upset she was (...) she was on her own for about 11 years and I was on my own for 4 years with the two boys. We were on our own and we just came to the club and that was us ever since. And I know it is not her but it's this dementia, so I know she is not doing it on purpose.

### 3.2.5 Preserving Normality

Another superordinate theme that emerged across all participants was *Preserving Normality*. This theme was discussed in rich detail by some participants and in particular depth by P03 and P05.

#### 3.2.5.1 Protecting Time for Self

This theme relates to the sub- theme *Growing Sense of Restricted Freedom*, all participants spoke of protecting time for themselves particularly to engage in pleasurable activities or roles outside the home;

Extract 46: P01: Lines 290-308

I do know that for me to continue to do the job properly, I do have to have some little time for myself, even if just to sit for an hour in the evening, plastering about with my craft work, watching something on the television or do crosswords or whatever, anything that's just for me. (Lines Suppressed) and I know this has to happen (...) it's like a safety net or something, or whatever you want to call it (...) I know I have to do it.

All participants recognised the importance of maintaining activities they find enjoyable, rewarding or relaxing for their own psychological well-being. Interestingly, P01 also made reference to the need to stay well in order to “do the job properly” thus, in a sense, justifying this time away as vital in order to continue caring for her husband.

As with P01's description of preserved leisure time as “a safety net”, participant narratives suggest that continuing with leisure activities and other roles is a way of cushioning themselves against future changes, by having a separate life of world which presently remains untouched by their spouse's diagnosis and the implications of this;

Extract 47: P02: Lines 166-177

P02: See I do keep myself busy, on the Sunday, if there's football on the Saturday, I go down and clean up the football hospitality rooms and I've taken that on 'cause I've got me to do something...Maybe I'm selfish. But it helps to keep busy, oh yeah (...) definitely, it helps me from thinking, “Well this is me” (Lines collapsed)

*I: You mentioned that it “helps”, can you tell me a bit more about that...is that okay?*

P02: Well if I keep busy, I know...I feel as if I've got my own little, wee life (...) I retired in July and now I wonder how we are going to manage in the house, all day and all night together but it has to come, that has to come.

As this excerpt exemplifies, a small number of participants talked about how keeping busy with leisure activities and other roles can act as a means of distraction (see *Cognitive Avoidance*) which prevents them from focusing on the future or becoming overwhelmed by their current situation;

Extract 48: P03: Lines 105-120

P03: You can't do anything about it you just adapt you know.

*I: Adapt? Would it be ok to tell me more about that (...) how you've adapted?*

P03: My body's jiggered but my mind is sharp so I have to keep my mind active and I couldn't just sit and watch television all day. I could get a good book and I can't put it down, I get lost in it and I'll do my sewing (...) I try and keep active mentally, I have my own little hobbies, sometimes when it gets bit too much.

### **3.2.5.2 Using Services and Family Support**

A smaller number of participants discussed relying on others (including family members and professional services) to help them. Whilst this theme is not spoken in great depth, participant narratives suggest that such support and services are highly valued as they potentially allow them the opportunity to continue with important activities and roles outside the home (see *Protecting Time for Self*);

Extract 49: P01: Lines 279-284

P01: I know myself that I have to use this time wisely if I get the chance and this is why I would like him to keep going out with [support worker] and go to the drop in centre, because eventually if I can get him into a routine, I will be able to take him there and leave for him and go for three hours and that is enough time for me to do something for myself, to meet somebody for lunch or to do something.

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Extract 50: P03: Lines 139-143

P03: Really, it's been a life change but my daughter has been a godsend (...) she's been my rock. She's like a breath of fresh air, walking in and she takes her dad out on her day off to the pictures and it gives me a bit of a break. Knowing he is being taken care of, and having a good time and I can just have a wee breathing space, and knowing she will be there.

In Extract 42 P03 also discussed how their daughter helps by engaging her father by activating positive shared memories. Indeed, a small number of participants

recognised the value of family, friends and support services, not only in maintaining normality for themselves but for their spouse, encouraging them to continue with tasks and activities “as usual”, in other words preserving the “personhood” of their spouse;

Extract 51: P04: Lines 277-296

P04: [Husband]’s brother’s good (...) he’s great ‘cause [Husband] still likes a line to go to the bookies with (Lines Suppressed) They’ll go over to the bookies together and [Husband] will say, “Well will you put it down for me?” and [Husband’s brother]’ll say, “No, just come with me”, and they’ll go and [Husband’s brother] will make him put over his money, his £2 or whatever and his line written properly and make him do it. And I think that’s invaluable stuff and I love [Husband’s brother] for doing it (...) I love him for doing it.

*I: How does that help?*

P04: Well for keeping [Husband] going, you know keeping his mind active. And also giving me a bit of support ((laughs))...

### 3.3 Key Relationships Between Themes

The first superordinate theme *Getting an Answer* identified from participant narratives suggests the initial reaction or meaning attached to a dementia diagnosis is something which is needed and actively sought, as participants recognise its importance and necessity for the present and future care of their spouse. The remaining superordinate themes encapsulate a process whereby participants attempt to adjust to the meaning of their spouses’ dementia diagnosis, once it has been obtained. The themes (*Losses and Changes for Self* and *Changes in the Marital Relationship*) represent participants’ subsequent realization of what the dementia diagnosis actually means for them and their spouse. Whilst *Limiting the Emotional Impact of Diagnosis* and *Preserving Normality* describe the strategies adopted by participants in order to maintain a sense of status quo for themselves and their marital relationship and limit the negative emotional consequences associated with these actual and anticipated losses and changes. The stages involved in this process are represented diagrammatically below:

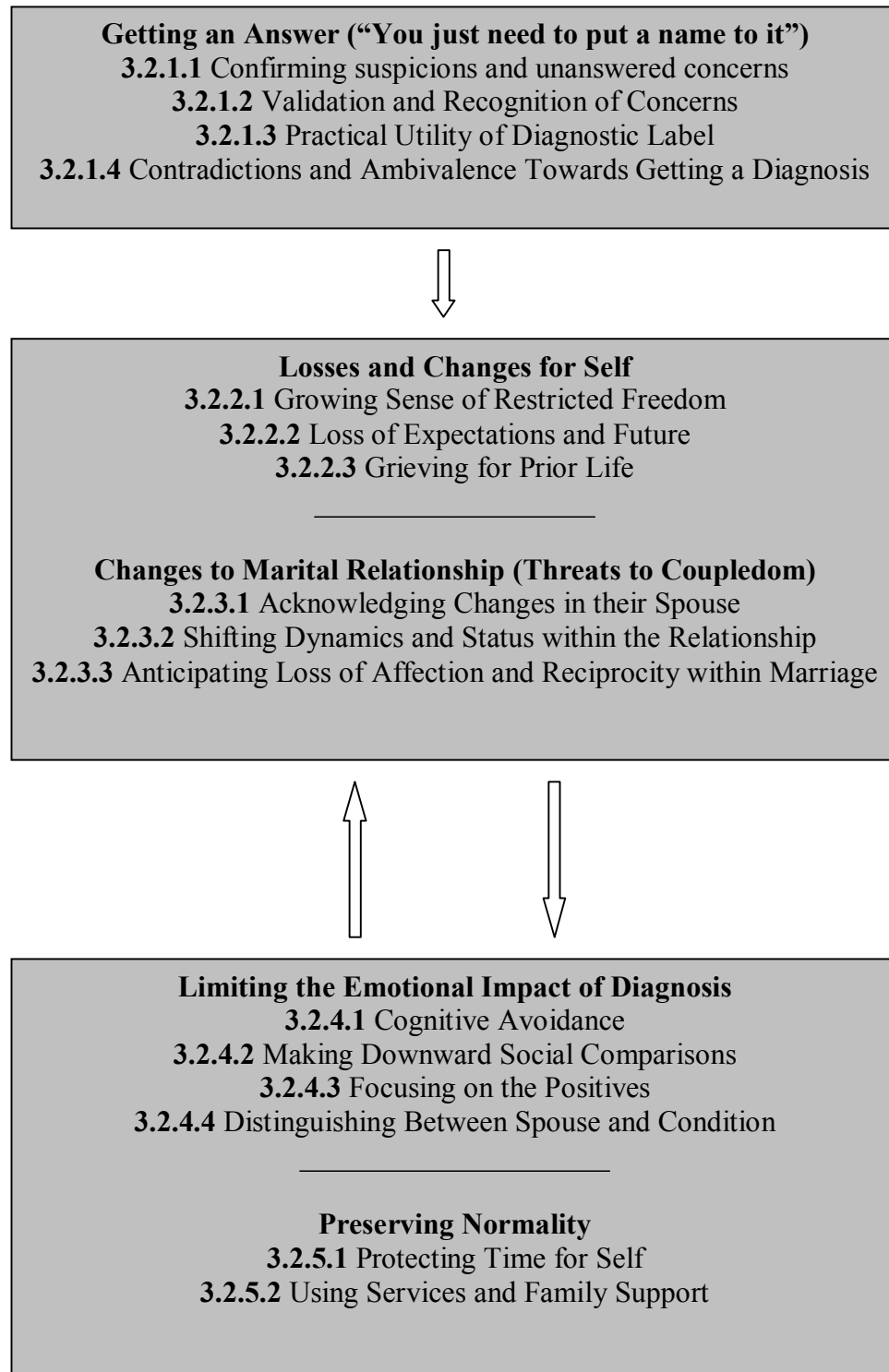


Figure 3: Identified Superordinate Themes and Sub-Themes Relating to the Meaning and Impact for Participants of a Dementia Diagnosis in their Spouse.

### 3.4 Researcher's Personal Reflections

Willig (2001) emphasises the importance of transparency in qualitative research; recommending that researchers should, where possible, make the reader aware of the ways in which the researcher's own experiences, beliefs, theoretical orientations and personal identity may have shaped or influenced the research. For this reason, I kept a reflexive diary during the entirety of the current study. I used my reflexive diary to record and explore my experiences and reactions to participant interviews, and the process of transcribing and analysing their accounts. Extracts from this diary are discussed below.

In the diary entry following my first interview I record some of my apprehensions about using a qualitative methodology and a feeling of responsibility towards my participants and attempt to do their accounts "justice";

Extract 52: 21/03/2008

Completed my first interview today, I really enjoyed this experience and feel I have some interesting material to work with. Sounds a little clichéd, I do feel humbled that this woman has been so honest with me about her experiences and now feel an added pressure as regards my thesis, possibly a sense of obligation or duty, to really understand what she is trying to say.

Later as I transcribe this interview, I continue to reflect on P01's experiences and I am struck by my response to the material;

Extract 53: 22/03/2008

Finished transcribing my first interview today. Listening to the account over over again is difficult. I don't think I was prepared for this, everyone I spoke to who had used qualitative for their thesis warned me about frustration, boredom and sore wrists with typing, but I am actually finding it quite distressing to reflect back on the interview as I transcribed. P01's discussion of not being able to go on holidays or enjoy things with her husband and her own activities makes me think of my parents. I spoke to them on the telephone today as they had returned from a weekend away. Their retirement seems to have given them a new lease of life, they are always away together or taking on new hobbies. I wonder how it would affect them if they believed these opportunities were taken away from them?

At this point my emotional response to the interview has made me concerned that such a reaction may influence subsequent interviews and analysis. Although, there is no history of dementia in my family, it became all too easy to make connections to

my own life and reflect on how I or my parents, who have entered into retirement, might feel in that situation.

During the interview process I also began to reflect on my own clinical practice and, as a trainee clinical psychologist, the role I play in the assessment and diagnosis process;

Extract 54: 01/04/2008

Feeling a little guilty during the interview with P05. When she talked about her experience of meeting with [Consultant Psychiatrist] and how she felt ignored and made to take a back seat. It made me think of my own how do I treat the spouses and family members of my patients during assessment? Do I take the time to listen to their concerns and worries? Do I “use” them to get the information I need, like a “live assessment measure”? How often do I reflect on what this process must be like for them and how do they feel when we, the professionals, leave? I suppose whatever else comes of this thesis it will definitely make me reconsider my role and interactions with family members in the future.

As I met with participants, I was aware of my *other* role as clinician, and was concerned that my participants viewed me in a certain way which may have made them reluctant to talk about certain experiences or be honest with their views.

As I began my analysis and reflecting on the emergent themes, I realised it is impossible to carry out this type of research and remain completely distanced, and not reflect on wider or personal issues. However, I grew concerned my analysis would suffer because of this. This fear of personal bias or influence became more salient following the death of the grandfathers of two friends within the space of two weeks. Both these gentlemen had been diagnosed with dementia;

Extract 55: 13/05/2008

Coding was particularly difficult today. Hearing [Friend] talk about her grandfather has reminded me of what the outcome of a dementia condition is. I wonder do my participants experience similar reminders? I am finding it hard to continue with my coding as I am worried that the events of the past two weeks will influence my interpretation of the interviews. Themes of loss have emerged in the narratives I have coded so far, but I am concerned that my friends’ bereavements have made this theme more salient for me.

Continuing with my coding, I began to question whether these experiences have led me down a particular path. Was I becoming focused on themes of loss as the connection between dementia and loss was foremost in my mind at this time? I

recalled how one participant asked frequently throughout the interview, *“Is that ok, is that the kind of thing you are looking for?”* I worried I was searching for “the right answer” as opposed to being open to the unexpected. As time went on, I felt under pressure to complete the analysis process and my concerns about coding escalated and feared I was not allowing sufficient time to reflect on each participant account;

Extract 56: 28/06/2008

Coded my sixth interview today. There is so much information to consider...How do I make sense of all this. I feel like I am lost in the data. Am I really capturing what my participants are saying? Am I listening to their stories? Feel like I will never get this done.

However, as themes began to emerge I felt I was getting more of a sense of what my participants were trying to say. Sharing my results with other professionals aided in this process as they shared “anecdotal” experiences from their own clinical practice which appeared to support my interpretation. Until this time, my concern was that I was somehow “missing” something, but discussing my themes with supervisors, colleagues and qualitative researchers, helped reignite my enthusiasm for this research. This was compounded when I shared the themes with participants, (See below);

Extract 57: 08/07/2008

Feeling a little better about things now. It really helps to talk to people about my themes. Talking to people more experienced in qualitative research and work clinically with older people has really helped.

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Extract 58: 18/07/2008

Feel enthusiastic about my research again, remember why I wanted to explore this. I was very nervous about sharing my themes with a participant for the first time, as their feedback mattered most I was worried about what they would think. Would they think I have not listened to what they were trying to say? Would this process upset them? Felt almost a sense of relief when P05 agreed with the findings. I kept thinking back to my first patient as a trainee and how nervous I was in feeding back my formulation. There was a similar feeling today.

In general, the entries in my reflexive diary highlight my anxiety throughout this process that somehow I would not find the “right” interpretation. However, with time I was able to acknowledge that this is one of the aspects of qualitative research that I



will have to accept; that there is no neat, correct answer to my question, people are complex and therefore any account of their experiences will reflect this.

### 3.5 Participant Reflections

Three participants were randomly selected to meet with the researcher (P01, P05, P08). The emergent themes, with a selection of supporting extracts, were presented to participants. These meetings served as a form of respondent validation, obtaining participant views on the credibility of the themes.

All three participants expressed their general agreement with the themes and that they represented their own experiences. All participants stated they agreed with some themes more than others which supported the variation in the spread and depth of themes across participants (see Appendix VIII). For example P05 said she had experienced changes and losses both in terms of her relationship with her husband and more personal losses for herself, however she distinguished between the two in terms of their significance;

Extract 59 P05

I suppose for me, the changes I have noticed for myself, not getting away walking anymore, not getting on holidays, not knowing what is next, that is the hardest to deal with. See I know things have changed for my husband and our relationship but maybe I kind of expected that (...) I didn't think things would change so much for me. Maybe it is different for other people.

This suggests whilst there may be similarities in experiences, individuals attribute different meaning or significance to them.

Although, qualitative interviews are not intended to have a therapeutic value, all three participants described their involvement in the research a positive experience, as P08 remarked;

Extract 60 P08

It was the first time anyone had asked me how *I* was talking things.

All participants also expressed feeling reassured that others had gone through similar experiences. P01 expressed concern that her account had appeared “*negative*” and the belief that others shared her experience had reassured her.

It must be acknowledged that this is only a subsection of participants and there is also the possibility that, due to perceived power differentials, participants were reluctant to “disagree with the researcher”. However this preliminary feedback suggests agreement with the emergent themes and interpretation of the narratives.

## 4. REFLECTIONS ON THEMES

This section includes reflections on each superordinate theme with reference to the relevant literature, including studies which have been reviewed in the Introduction Chapter to this thesis. Where there are discrepancies with the findings of previous work, these will be highlighted and discussed. This will act as a means of triangulation as well as a discussion of how this study contributes to the knowledge base within dementia care.

### 4.1 Reflections on the theme *Getting an answer (“You just need to get a name put to it”)*

Participant narratives suggest their main reaction to the diagnosis disclosure was a sense of confirmation of suspicions they had already held. Robinson et al.’s (2005) study of couples’ reactions and adjustment to a dementia diagnosis supports this theme, finding that a diagnosis merely “confirmed a problem” for the couples and, in some cases, was a source of relief as it allowed for a greater understanding of what was happening. Additionally, Smith and Beattie (2001) also found that patients and family members who have recognised changes in cognition and have suspicions about what may be wrong, may have begun the process of acceptance before a diagnosis is officially disclosed.

All participants subsequently acknowledged practical benefits associated with the diagnostic label, which is consistent with the quantitative literature (See Section 1.5.2). The disclosure literature indicates that caregivers view a timely diagnosis as essential to facilitating access to treatment (Smith & Beattie, 2001; Wackerbarth & Johnson, 2002; Byszewski et al., 2007) and to allow planning for future and access to support services (Connell & Gallant, 1996; Holyroyd et al., 2002). Of particular note in the current study is that participants talk in less depth about the practical utility of a diagnosis. Whilst this is acknowledged in the majority of narratives, it was usually not expanded on greatly. It is possible this issue was more salient to

participants prior to the diagnosis, and dwelt on less, post-disclosure as they focus on what the diagnosis means. Indeed, the theme *Contradictions and Ambivalence towards Getting a Diagnosis* highlights the complexity of the participants' attitudes towards obtaining a diagnostic label. Whilst the majority of participants in the current study acknowledge the utility of a diagnosis, half also discussed being almost resigned to the fact there was no cure and thus a diagnosis may mean no more than a confirmation of a chronic, progressive condition which participants associate with physical and cognitive decline (Connell & Gallant, 1996; Drickamer & Lachs, 1992). Robinson et al.'s (2005) study also indicates a division between participants in their perception of the usefulness of gaining a diagnosis. The current research suggests the situation is less straightforward for some participants who hold simultaneous, contradictory views towards the need for a diagnosis (Extracts 10 to 12). This ambivalence may reflect for those participants the distinction between accepting the "fact" of a diagnosis and accepting the personal meaning of the condition for themselves and their spouse (Young, 2002) (Extract 12).

## **4.2 Reflections on the theme *Losses and Changes for Self***

As discussed, there is a lack of research which explores the meaning of a dementia diagnosis for spousal caregivers in the early, post diagnostic stage, thus there is limited knowledge about the specific personal losses experienced during this transitional period. The care-giver literature however has identified a range of losses associated with the mid-late stages of the condition including the loss of personal and social roles and activities (Dempsey & Baago, 1998; Husband, 2000) along with the loss of a confidant in their spouse and grief following their eventual death (Hubbard, 1994; Beeson, 2003).

In one of the few, post-diagnosis studies, Robinson et al.'s (2005) exploration of couples' responses to a dementia diagnosis conceptualises this period as a time of making sense of and adjusting to loss. Whilst that study highlights the process of *couples* coming to terms with perceived losses and the strategies adopted to minimise these changes and their impact, it is less clear on the nature of personal

losses experienced specifically by the non-diagnosed spouse within the marital dyad. This is despite the possibility that such losses may be linked to the increased prevalence of depression in spousal caregivers and thus be a potential target for intervention (Cuijpers, 2005).

Studies carried out with family carers several years post diagnosis have reported a loss of social and recreational interactions and a loss of control over life events (Aneshensel et al., 1995; Loos & Bowd, 1997; Ory et al., 2000). The identified theme *Growing Sense of Restricted Freedom*, however, suggests that, for some participants in the current study, this process of loss has already begun in the early, post diagnostic stage. Whilst some participants report still engaging in pleasurable and rewarding leisure activities and social interactions, they can no longer do this with the same freedom of choice (Extracts 13 and 14) and a growing sense that they may not be able to do so in the future (Extract 20). Some participants in the current study described a loss of freedom, not only in terms of daily activities and plans but also a sense of growing restriction as regards their entry into the role or position of carer (Extract 15). This perception of possibly being “engulfed” in the care-giving role has been associated with a greater sensed loss of self (Skaff & Pearlin, 1992; Aneshensel et al., 1995) and greater levels of depressive symptoms (Van den Wijngaart et al, 2007). Thus the presence of this theme in the narratives of some participants in the early, post-diagnostic stage is of significant concern. Of particular interest in the current participant narratives was the theme *Loss of Expectations and Futures*. This has not been identified as a feature of later caregiving stress and adjustment in other research (Aneshensel et al., 1995) and thus it is possible this may be a unique concern for the post-diagnostic stage. Participant narratives suggest at this stage they are adjusting to experienced and anticipated losses in the present and future as well as the past.

The subordinate theme, *Grieving for Prior Life*, suggests that for some participants in the early stage have begun a process of grieving for the life or “self” they were prior to the diagnosis. Loss of self in care-giving is associated with the loss of roles and activities which the carer previously found a purpose or self-validation in (Skaff

& Pearlin, 1992) or the loss of significant others who provided confirmation of self-referent knowledge (including their spouse with dementia) (Beeson, 2003). Aneshensel et al. (1995) found carers generally did not experience a complete loss of self and actually were more likely to report positive changes in self concepts as a result of care-giving. This appears contradictory to the current findings of the current study which suggests many of the spouses interviewed do experience a grieving process for themselves. However, the majority of participants in Aneshensel et al.'s study were surveyed several years post diagnosis. In the current study, in the more immediate post diagnosis stage, participants experience not only a loss and restricted freedom in their present life but a loss of their anticipated futures (*Loss of Expectations and Futures*). At this early stage there may not have been the opportunity for participants to reflect on the positive aspects of the caring role, which may lessen the sense of role captivity (Aneshensel et al., 1995). O'Connor (2007) found that family members do not immediately see themselves as carers and it is a gradual process before they acknowledge the possible benefits of this position. Indeed, only one participant reflected on positive aspects of their new responsibilities or tasks. It is possible that in the post-diagnostic stage, participants are preoccupied with adjusting to the above experienced and anticipated losses. Liiceanu (2000) argues that an important component of adjusting to an actual or sensed loss is to go through an initial grieving process for the old self and previous hopes and expectations before accepting a new life, accommodating new roles and redefining one's self-identity. As discussed, Gallagher-Thompson and Steffen (1994) found that brief psychodynamic psychotherapy was more effective with those who had been caregivers for a shorter duration. The authors considered this result unexpected and could only hypothesise that their finding related to perceptions of loss at this time. The findings of the current study can be understood with reference the Gallagher-Thompson and Steffen (1994) findings, by suggesting that adjusting to personal losses, particularly the loss of a planned or even potential future is of particular concern to some participants early on in the dementia process.

### **4.3 Reflections on the theme *Changes in Marital Relationship (Threats to Coupledom)***

Narratives indicate in the early, post diagnostic stages, a significant concern for participants is what a dementia diagnosis means for their marital relationship. The theme *Acknowledging Changes in their Spouse* reflects participants' growing awareness of differences in cognitive functioning and temperament in their spouses. Participants also perceived a shift in their spouse's contribution to family roles and relationships. This theme was also identified in Robinson et al.'s (2005) study, who found that spousal carers made negative assumptions about what their partner with dementia could remember which, when discussed in the presence of the person with dementia, resulted in negative shifts in mood and a decrease in self-confidence in the dementia spouse.

Of particular significance is participants' acknowledgement, not only of current changes in their spouse, but the meaning they attach to these changes. A common concern among participants was that minor and specific changes are symbolic precursors to the future loss of the entire "person" of their spouse (Extract 24). Research has indicated family caregivers of people with dementia experience a grieving process for the "person" of their spouse prior to their physical death (Hubbard, 1994; Walker, 1995; Almberger et al., 2000; Li, 2005). The current participant narratives suggest they anticipate going through such a process in the future. This sense of losing the "person" of their spouse as a result of the dementia process, has implications beyond the well-being of the carer. As discussed in Section 1.1.2, Kitwood (1997) argues that others (including family members and spouses) guarantee the status of personhood and positive social interactions with significant others are necessary to this safeguarding process. Thus it is significant that even at early stages participants perceive cognitive and behavioural changes as heralding later losses of personhood.

The theme of *Shifting Dynamics and Status within the Relationship* is consistent with the findings of Robinson et al. (2005), who identify a process whereby the carer

spouse's role within the marital relationship changed as he or she, in effect, became a carer. Similar to the narratives of the current study, participants reported taking on more responsibility for tasks and chores in daily life. However, the current study adds to the understanding of the complexity of this process as participants reported a sense of responsibility to protect their spouse not only physically, assisting them with daily tasks, but also protecting their emotional well-being by limiting the losses they are experiencing during this stage. A number of qualitative studies which explore the strategies couples use in order to live positively with dementia (Keady, 1999; Helmstrom, et al., 2008) suggest that one of the main concerns of the non-affected spouse is to maintain the involvement of the person with dementia in daily life in order to maintain their sense of self for as long as possible. As discussed, participants in this study fear they will eventually "lose" the person of their spouse, and this anticipated loss is associated with a sense of sadness for themselves as they fear losing their partner and confidant. Thus it may be that adopting a protective stance which limits potential losses for the person with dementia actually has benefits for both partners (Perry & O'Connor, 2002).

With these shifts in relationship dynamics, a number of participants expressed a concern that as they take on a more uni-directional caring role in the future, they will lose the more reciprocal exchange of affection including the romantic and physical side of the relationship. Baikie (2002) discussed how a shift in the dynamics of the relationship from adult-adult to parent-child can result in a change in attitude to sexual contact, which may be perceived as almost incestuous in latter stages. The loss of emotional attachment and support has been associated with a sense of "relational deprivation" (Beeson, 2003) and puts care-giving spouses at an increased risk for psychological distress or depression (Aneshesl et al., 1995; Beeson, et al., 2000, and Besson, 2003). Whilst it must be emphasised that the loss of affection and reciprocity is mostly of an anticipated nature among participants in this study, this may be a significant source of distress if they contemplate the possibility of caring for an individual with no return in affection.



#### **4.4 Reflections on the theme *Limiting the Emotional Impact of Diagnosis***

Participant narratives suggest they use a variety of cognitive strategies which help manage the meaning of their spouse's dementia diagnosis for themselves and their marital relationship. All participants reported they tried to avoid thinking about the "future" in particular the latter stages of the dementia condition, as this is associated with sadness and a sense of loss. This strategy of cognitive avoidance has been observed with people who have been recently diagnosed with dementia, who use this strategy as a form of denial technique that enables them to avoid acknowledging the eventual loss of functioning they will experience (Young, 2002; Clare, 2003). The current findings indicate that a number of participants discussed using avoidance-type strategies. Hellstrom, et al. (2008) argue by limiting focus on the future and potential losses couples, where one partner has a dementia diagnosis, are able to make life as meaningful as possible. Hellstrom, et al. (2008) found that couples aim to ensure the quality of their lives and relationships by searching for the positives within their relationship and continuing to find "small joys" and pleasurable routines in their days. Robinson et al. (2005) also found focusing on the positive was an adjustment strategy used by couples post diagnosis, whereby they strive to remember happier times and positive aspects of their relationship as a whole. With some participants in the current study, who are anticipating a future loss in reciprocity and affection within their relationship, holding in mind positive aspects of their marital relationship may help aid the adjustment into a caring role by fostering a sense of closeness with their partner. Baikie (2002) describes satisfaction with the marital relationship as a balance between costs (caregiving) and rewards (a good "pre-morbid" relationship), thus reflecting on the positive aspects of the pre-diagnostic relationship may help spouses to perceive caregiving (a potential cost) as a more equitable exchange.

Another technique, also reported in the current study, which appears to help participants preserve a positive marital relationship is by distinguishing between their spouse and the condition of dementia. O'Connor (2007) argues that appraising

“annoying” or “hurtful” behaviours as symptoms rather than a personal attack by the person with dementia, facilitates greater patience and understanding by the caregiver spouse. The labelling of the symptoms with an official diagnosis may facilitate this strategy (Smith, et al., 1998).

In the current study participants also adopt cognitive appraisal strategies which appear to reduce the negative emotional impact of a dementia diagnosis on their own self-identity and self-esteem. Participant accounts include frequent comparisons to others who they believe are in less fortunate situations or who have experienced greater stress or suffering. Comparing oneself to others perceived as worse off has been found to elevate self-esteem (Taylor, 1983; Gibbons, et al., 2002). For the spousal carers in the current study who are experiencing a threat to their past and future selves, this strategy may help protect against lowered self-esteem by casting themselves in a more positive light and making their own situation seem more manageable (Young, 2002).

#### **4.5 Reflections on the theme *Preserving Normality***

As well as adopting strategies that help manage or restructure the “meaning” of a dementia diagnosis, participant narratives suggest they also actively seek to directly manage the situation itself (Aneshensel et al., 1995). In response to feared losses in the future, participants emphasise the importance of preserving roles and activities at this time. Participants report that having time for themselves where they can pursue activities they find enjoyable or gain a sense of purpose helps minimise negative emotional reactions such as sadness and frustration. Robinson et al. (2005) also reported, as well as valuing time together with their spouse, care-givers found having a day away from their spouse an important way of coping. It is possible this drive to maintain a separate space and continue with participation in activities outside the care-giving relationship represents an attempt to protect against threats to a valued social-identity following the diagnosis (Husband, 2000). Indeed, Kristensson-Ekwall, et al. (2006) found maintaining interests outside the caring situation was associated with better perceived quality of life in caregivers.

As highlighted in Excerpt 47, participants express concern that such actions will be perceived as selfish, and others report feeling guilty at the thought of “abandoning” their spouse. O’Connor (2007) also found that caregivers describe feeling a sense of guilt when they “took care of” or “re-centred” themselves, as this appears to go against societal expectations of caring. As with the O’Connor study, current participants attempt to lessen this guilt with the rationale that it is necessary to maintain one’s own well-being in order to care for another. This time for oneself has always been important for these participants, however there is now a sense that this must be justified.

Participants discussed how the support of others was also vital to help limit losses post diagnosis. Aneshensel et al. (1995) identify two separate components of social support which aid in the containment of care-giver stress: firstly, by providing instrumental support (practical support and assistance with physical acts of caregiving and domestic chores) and socio-emotional support (someone to confide in and help bolster mood). Participant narratives currently suggest that in the post diagnostic stage, the value of social support is in helping to limit or protect against the losses to themselves and their relationship, rather than division of caregiving or domestic tasks. By others participating in activities with the person with dementia, participants are able to use this time to continue with pleasurable activities on their own which is particularly important in maintaining a positive emotional state and buffering against threats to self esteem (See Section 3.2.5.1). A second, highly important function of social support in these early stages appears to be helping participants provide a scaffold to protect the “personhood” of their spouse with dementia by encouraging participation in “usual” and positive activities and activating positive shared histories. Robinson et al. (2005) also found relationships with other family members and friends influence adjustment to loss, by helping to protect a valued social identity for both partners.

## 5. FURTHER REFLECTIONS

The following section will begin with a summary of the current research findings. This will be followed by a critique of the current investigation including methodological limitations. The implications of the current findings for theory and clinical practice will be considered and areas for future research discussed.

### 5.1 Summary of Research

Eight participants took part in the current study (seven female and one male). The age of participants ranged from 60 to 77 years. The time since their spouse's diagnosis ranged from 2 months to 15 months. Participants were recruited from patients referred to the Early Stage Dementia Service within the local area Community Mental Health Team.

The current study employed an IPA qualitative methodology for the purposes of analysis (Smith, 1996; Smith & Eatough, 2007). Data was collected via semi-structured interviews and transcribed verbatim. The aim of this study was to explore the experience of the disclosure of a dementia diagnosis for spousal caregivers and the meaning and impact this has on their lives.

Analysis of the interviews revealed superordinate themes which appear to capture the experience and meaning of a dementia diagnosis for spousal caregivers and how they adjust to these changes.

The superordinate theme *Getting an Answer* represents participants' appraisal of the diagnosis disclosure as something that was not unexpected, confirming what was already suspected (*Confirming Suspicions and Unanswered Concerns*) and thus validated concerns which had not been acknowledged by others (*Validation and Recognition of Concerns*). Participants also viewed a diagnostic label as something they needed in order to access treatment, services and support (*Practical Utility of Diagnostic Label*). Within this superordinate theme there was also a sense of

ambivalence towards the diagnosis in recognition of the lack of a “cure” and the limits of the support available at this time (*Contradictions and Ambivalence towards Getting a Diagnosis*).

The superordinate theme *Losses and Changes for Self* reflect the personal meaning of a dementia diagnosis as participants conveyed a sense of restricted freedom and lack of autonomy as well as a loss or denial of their expected futures. Participants also expressed a sense of grieving for their past selves and lives.

Participants also experienced *Changes in the Marital Relationship*. They perceived changes in their spouse which were associated with a shift in the dynamics of the marital relationship with caregivers becoming more protective towards their spouse. These changes in dynamics were related to an anticipated loss of intimacy and reciprocal exchange within the marriage.

Participants engaged in a range of strategies while *Limiting the Emotional Impact of the Diagnosis* for themselves and their marriage. These included cognitive avoidance strategies, making downward social comparisons, focusing on the positive aspects of their lives and relationship and distinguishing between the upsetting symptoms of dementia and the person of their spouse.

The superordinate theme of *Preserving Normality* reflected how participants attempted to directly manage the losses and changes they had experienced, including protecting time for leisure and social activities and using services and family support.

The above superordinate themes reflect the process by which participants acknowledge the end of a search for a diagnostic answer and begin to make sense of the implications of the diagnosis for themselves and their marriage. These losses and changes are something which participants adjusted to using a variety of strategies.

## 5.2 Methodological Critique

### 5.2.1 Strengths

As far as the author is aware this is the first study which has focused specifically on the meaning and impact of a dementia diagnosis for spousal caregivers alone. In previous research examining the diagnostic and post-diagnostic stage, caregivers have been included merely as a means of triangulating the accounts of the person with dementia or they have been involved in discussion of shared experiences. In such an environment the personal losses and changes experienced by caregivers, may be unintentionally neglected or be overshadowed by the more salient changes and losses experienced by the person with the diagnosis. Interviewing spouses alone has allowed an insight into their own individual losses and the strategies they use to make sense of and adjust to these. The dissemination of these findings will hopefully contribute to the knowledge and understanding of professionals involved in diagnostic and post-diagnostic dementia care and facilitate improvement in communication and support for caregivers (See Section 5.3).

The use of a qualitative methodology to achieve these ends has allowed a richer exploration of the meaning of a dementia diagnosis and thus possibly accesses aspects of this experience which may have been missed using quantitative survey methods. The use of qualitative interviewing techniques has allowed participants to talk in greater depth which has highlighted some of the complexities of their experiences. As demonstrated in the emergent theme *Contradictions and Ambivalence Towards Getting a Diagnosis*, participants hold conflicting views about the diagnosis as something that is needed but not wanted. The use of semi-structured interviews allows this sense of contradiction to be pursued in greater depth, thus going beyond the relatively simplistic method of rating the pros and cons of a diagnosis.

## 5.2.2 Limitations

Although participants were recruited into the study as close to receiving the diagnosis as possible, for many there was an interim of at least several months between the disclosure of their spouse's diagnosis and the interview. Participants' accounts of their initial reaction and meaning subscribed to the diagnosis were therefore retrospective recollections which may have been influenced or biased by subsequent experiences. It could be argued the accounts of their initial reaction to the diagnosis have been shaped by the events of the intervening months, which may have included further changes in their spouse's condition. Additionally, their views of the meaning of a diagnostic label may have altered as they are provided with information by health professionals post diagnosis about the prognosis and nature of their spouse's condition. This time lag between diagnosis and interview is an area to be considered in future research.

In evaluating the quality of the data analysis in the current study, the impact of sequential analysis must be acknowledged. Miles and Huberman (1994) argue that a number of factors may bias researchers in attaching more weight to certain participant accounts for example, "*the informant may be articulate and reflective and may enjoy talking about events and processes*" (page 268). Additionally, the circumstances of data collection may bias the strength attached to participant accounts. Miles and Huberman contend that data collected early or first may influence subsequent interviews or the analysis of subsequent transcripts. In the current study Participant 01 (who was interviewed and analysed first) was particularly articulate and her experience as a carer for her two adult sons may have made her more reflective on the meaning of her husband's diagnosis. Indeed, out of the 51 extracts used in discussion of the sub-themes, 12 were taken from Participant 01's narrative. Although attempts were made to limit this potential bias (leaving as long a time gap as possible before commencing analysis of subsequent transcripts; multiple coding using other participant narratives and use of the researcher's reflexive diary) it is possible this first narrative influenced in some way analysis of subsequent accounts.

IPA methodology recommends the use of a homogeneous sample (Smith & Eatough, 2007). However, the sample of participants in the current study included a mix of female and one male participant. The literature suggests that male caregivers may have qualitatively different experiences to their female counterparts and view the role of caring in a different way (Horowitz, 1985; Skaff & Pearlin, 1992; Ory et al., 1999; Beeson, 2003). The inclusion of only one male participant prevents any analysis of whether differences in his narrative are gender related as there is no means of comparing with other male carers. Future research would therefore benefit from an exploration of the meaning and impact of a dementia diagnosis specifically for male spouses.

Although qualitative methods make no claims to generalisability, the caveat must be acknowledged that the current participants are generally homogeneous in terms of socio-economic, cultural and ethnic backgrounds. It is possible that cultural and contextual variables may influence attitudes to caring for family members and thus impact on the meaning a dementia diagnosis has for family members (Czaja, et al., 1999). Future research may explore the current research question within a wider demographic with a particular need to elucidate on the experiences of different ethnic and religious groups.

### **5.3 Implications for Clinical Practice**

Based on the emergent themes in the current study and discussions with participants, a number of recommendations can be made for clinical practice and the provision of dementia care services.

In the current study, participants acknowledged the importance of post-diagnostic services, with particular reference made to the Early Stage Dementia Service, a highly valued source of information and practical support. The role of this service includes providing advice on accessing financial benefits available to the person with dementia and their carers, facilitating access to relevant services such as support workers, respite and adult day-care services and charitable organisations such as



Alzheimer's Scotland. All participants discussed the value of this service and the support it provided. This finding differs to Robinson et al. (2005) who reported that participants in their study found the post-disclosure information and support insufficient, which was associated with feelings of isolation and helplessness in both individuals with dementia and their spouses. The current study emphasises the need for such a service. For family members and spouses, who may have felt isolated during the assessment period, the provision of timely and ongoing support post-diagnosis may help redress this sense of isolation and challenge the belief they will have to cope alone.

An analysis of participant narratives suggests receiving a dementia diagnosis in their spouse heralded a time of change and multiple losses. Participants appear to go through a transition period whereby they acknowledge the possible loss of a previous way of life for themselves and the denial of the future they had anticipated for themselves. It is possible that timely psychological intervention to support adjustment to these losses may prevent later psychological difficulties. Indeed, these findings support the recommendations of Gallagher-Thompson and Steffen (1994), Moniz-Cook and Woods (1997) and Robinson et al. (2005), emphasising the need for psychological and psychosocial interventions at this time. Gallagher-Thompson and Coon's (2007) review of evidence-based treatments for dementia caregivers identified a gap in knowledge about the type of interventions which are most effective for different types of caregivers (spouse versus adult-child; male versus female) and what works best at different stages of the dementia condition. The findings from the current study have contributed to an understanding of the issues most relevant for spousal caregivers during the post-diagnostic stage. The themes identified suggest that a focus for early stage spousal caregiver interventions should be supporting adjustment to loss, as participant narratives convey that a sense of personal loss is particularly salient for this group of caregivers at this time.

This study also highlights the need for post-diagnostic support to be made available to caregivers separate to the person with dementia, as caregivers experience their own personal losses and changes which they may feel reluctant or unable to express

in the presence of the person with dementia or other family members for fear of burdening them with guilt or concern at an already stressful time. O'Connor (2007) contends that caregivers and care-receivers are likely to have divergent and, in some cases, incompatible needs, and where possible, services should acknowledge both. Thus post-diagnostic support targeted at only the person with dementia may not have any beneficial impact on caregivers who are going through their own period of adjustment (Sorensen et al., 2002). In the provision of post-diagnostic psychological and psychosocial support, it should be recognised that caregivers may have developed their own personal coping strategies (as suggested in the present study). Services should seek to identify and maximise these where possible.

In the process of sharing the emergent themes with participants, a number expressed how it had helped to realise that others were going through similar experiences and that they were not "*going about this wrong*" (PO5). It may aid post-diagnosis adjustment for carers to be able to share their experiences with others in an apparently similar situation. In Scotland, services such as Alzheimer Scotland frequently run carer support groups and events and it may benefit caregivers to be made aware of such services during the post-diagnostic period as a forum to share experiences and coping strategies. O'Connor (2007) argues that care-giver groups or events may have an additional benefit by providing an avenue by which caregivers begin to develop a new positive identity through social interactions with others. This may help to protect against the isolation experienced by family caregivers who may perceive their "prior self" as lost or under threat.

The findings of this study may also have implications for pre-diagnostic and assessment care. Participant narratives revealed many spouses felt unsupported by health professionals when they initially raised concerns about their spouse, particularly within primary care services such as their General Practitioners. Thus an area for potential intervention may be to offer further training in dementia care to GP services with the goal of improving communication and interactions with people undergoing assessment and their family members. The need for further training and improved communication between specialist and GP and primary care health

services is particularly relevant in light of the predicted increase in prevalence of dementia over the coming decades (HDL - 44, Scottish Executive, 2004).

Additionally, the findings from the current research could be incorporated into staff training for other health professionals involved in post diagnostic care and support for people diagnosed with dementia and their families. Sharing these findings with staff through presentations and discussion may act as a means of consciousness raising about some of the key concerns and issues for spouses of people with dementia. By increasing understanding in this way, staff within the relevant dementia-care services may be able to more appropriately tailor their input to families at this stage.

## **5.4 Possibilities for Future Research**

As discussed above the interviews in the current study were carried out retrospectively, and at one time point, sometimes several months post diagnosis. Participant accounts suggest a shift in attitudes over time with their initial reaction to the diagnosis being one of relief or confirmation, which becomes one of sadness, anger or injustice as they contemplate what their spouse's diagnosis means for them. Future research may seek to explore this process in more depth by adopting a longitudinal approach (which was not feasible within the time constraints of the current research). Coyle (2007) argues that longitudinal research may be of particular use with qualitative methodology, allowing researchers to explore how attitudes and meanings of a particular event or experience shift over time. In the case of a dementia diagnosis it may be of value to explore reactions within the first few weeks post diagnosis disclosure, and follow these up over the subsequent months and at the end of the first year. Additionally, future research may seek to capture the pre-diagnostic assessment period by interviewing care-givers following their initial referral to specialist assessment services such as Older People Psychology or Psychiatry services or specialist memory clinics.

Another scope for future research might be to explore the meaning of a diagnosis for different categories of carers. The majority of participants in the current study (all but one) were wives of the person diagnosed with dementia. As discussed, husbands may have qualitatively different experiences to their female counterparts, with Kramer (1997) identifying unique predictors of caregiver strain and coping strategies in husbands. Thus it may be worthwhile to explore the impact of a dementia diagnosis for husbands alone as it is possible that this experience has different implications for husbands and thus holds a different meaning. Similarly, adult child caregivers have not been included in the current study, despite the fact that adult daughters form a high proportion of dementia caregivers (Moriarty and Webb, 2000). Adult children may have a different understanding of caregiving as spouses may have already cared for a parent or sibling with a dementia diagnosis or chronic health condition (Sorenson et al., 2002). This previous experience may mean that spousal caregivers have different knowledge or perceptions of dementia and caregiving, thus influencing the meaning of a diagnosis for them. In this way, the current findings may not generalise to adult child caregivers.

Participant narratives in the current study highlight the importance of specialist post-diagnostic services such as the Early Stage Dementia Service. It may be worthwhile to explore using either quantitative or qualitative methods what aspects of this service are valued by people with dementia and their family members (the provision of information and advice, emotional support, connections to other services including charitable organisations and support workers). Such information would aid in the design and implementation of similar services in trusts where they are not offered at present, and point to areas of potential development within the present service.

## **5.5 Conclusions**

The present study has generated knowledge about individual's psychological responses towards a dementia diagnosis in their spouse, and how spousal partners adjust to the changes they face immediately post diagnosis. This contribution to the

caregiver literature is important given the lack of research exploring the issues specific to carers at this stage. This is despite recent health care policy recommendations that information and support be tailored to reflect the changing needs of patients and their families at each stage of the dementia condition.

The current study suggests that at the time of diagnosis of dementia spousal partners experience a period of adjusting to losses and changes for themselves and their marital relationship. These changes are linked to their past (past selves and lives); their present (activities, roles and relationships) and their future (with altered hopes and expectations). In general, the narratives in this study convey a sense of transition from spouse to that of carer. These findings may be of particular interest to health professionals involved in the assessment and diagnosis of dementia. It should be acknowledged that, despite their apparent acceptance of a diagnosis that was already suspected, this time heralds a number of challenges and losses for spousal partners.

In conclusion, the insight into responses to a dementia diagnosis in one's spouse provided by this study will hopefully be of benefit in meeting the needs of a group likely to grow in number as our population ages.

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